The experiences of Young Carers: Towards an understanding of stress and the development of psychophysiological resilience

Hawken, Tamsyn

Award date:
2019

Awarding institution:
University of Bath

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Acknowledgements

The research is clear, support is vital for resilience. Here, I'd like to express gratitude to those who have supported, witnessed and encouraged me over the last four years.

Thank you to the ESRC for providing me with a studentship, additional funding and incredible opportunities throughout my PhD.

Academically, I express my thanks to 'my Julies', Professor Julie Barnett and Professor Julie Turner-Cobb. Julie B, thank you for being on board from the start, for stepping in as first supervisor and your expert advice – you've taught me many things and I appreciate your guidance. Julie TC, thank you for planting the seed in that final year lecture, for taking a long shot on my MSc placement, helping me to secure PhD funding, continuing to supervise after your move and for generally always being in my corner and believing in me.

Thank you to all the inspiring young carers and families who generously gave their time, voices and stories to this research. It is enormously valued.

To my family, I extend gratitude and dear thanks. To Mum and Rich, you support me no matter what, even when it isn't exactly clear what I'm doing or what you're supporting (!). You welcomed me home and in the past few months especially, your company, financial support, laundry services and listening to me rant (thanks Mum) have been appreciated. I can always rely on you and that means a great deal. Dad, thank you for your financial support with this PhD but also in personal matters - starting me out on the path to regain my health and get my life back. To my late grandparents, I wish you could see this, but you helped to shape the person I am and in that sense, I hope you can live on in me. Thank you, and I love you all.

Dearest Tara, You've been the most incredible and steadfast support. I am so thankful to call you my best friend. I am so grateful we crossed paths. You have understood, offered advice and given perspective. Your unwavering support and friendship is a gift - I love you.

To my friends and colleagues, thank you for understanding, or seeking to understand this process and for providing encouragement and support. To my officemates, particularly Vangelis, Eleanna and Chiara - it has been a joy to share this journey with you. Gwen, Beth, Caroline, Teesh, Lau and Hope - thanks for helping me stay true to me and always being there.

To the Sisterhood under the Westwood, my precious circle of women who have journeyed with me over the last few years. You've been an incredible anchor, reminding me of what is important. Thank you for your witnessing, honouring and love. Shirley, I am so delighted we have become good friends. And of course, to dearest Lou, thank you for your friendship, generosity, kind heart, cheerleading and the soul medicine you provide through your work – I'm so lucky to have you (and your beautiful family) in my life.

To teachers, mentors and guides who have enabled me to continue my personal development over the last few years, something that is so important to me; Kym, Elise and Kalindi especially, thank you.

And last, but by no means least, I'd like to thank what I consider to be the 'Cornish Holy Trinity' - R-Jay, the Cornish Coast and Cornish pasties, for providing me with so much love, enjoyment, solace and comfort in the last few months of writing up this PhD. With these three, my family and my friends in my life, anything is possible.

Abstract

Background: The body of evidence surrounding adult and elderly carer outcomes is well established, however fewer studies have been conducted with young carers (those <18 years with caring responsibilities). Given the negative outcomes associated with caregiving, the experience can be conceptualised as a risk factor for health, requiring protective factors to promote adaptation. Positive outcomes have also been associated with caregiving, suggesting that protective factors and resilience may be inherent in the caregiving role. Protective resilience factors have been identified in adult and elderly carers, and are typically theorised within the three levels of the socioecological model of resilience (individual, community and society). Biopsychosocial research, from a resiliency perspective is necessary to identify the factors contributing to, and pathways towards, resilience, in order to promote positive outcomes in young carers.

Aims: The overall aim of the current research programme was to explore the mechanisms underlying psychophysiological resilience in young carers. Specifically, the aim was to identify protective factors which contribute to perceived stress, resilience and physiological outcomes in this population.

Method: A mixed methods, sequential design was used across three studies. First, a systematic review was conducted following Prisma guidelines. Second, qualitative photo elicitation interviews were carried out with young carers and analysed using thematic analysis. Finally, a quantitative study was conducted using questionnaires to measure psychosocial factors, and hair samples to assess hair cortisol concentration in young carers and an age-gender matched non-carer control group; data were analysed using statistical techniques including correlation, t-tests, regression and moderation.

Summary of findings: The systematic review identified that coping, social support, stress appraisal and carer activities contributed to carer adjustment and outcomes. Evidence was found for both the transactional model of stress and the socioecological model of resilience. The second study identified 11 factors within the three levels of the socioeconomic model of resilience. Individual factors included pre-empting challenges and planning ahead, cognitive strategies, emotional strategies and seeking solitude. Community factors included family support, friendships, and pets and inanimate objects. Societal factors included professional support, access to carer activities and community, being outdoors and disability aids. The findings of this study provided further support for the socioecological model and also identified potential protective factors in a population of young carers. The final study found that young carers reported significantly greater perceived stress than non-carers but did not demonstrate higher hair cortisol concentration. A negative association was found between perceived stress and resilience in young carers and non-carers, and a positive association between perceived stress and hair cortisol concentration was found in young carers. No significant associations were found between resilience and hair cortisol concentration. A relationship was found between perceived stress and benefit finding in the young carer group and no significant relationships were found between benefit finding and hair cortisol concentration in either group. Mediation analyses of benefit finding and resilience as mediators of perceived stress and hair cortisol were not run due to requirements for this analysis not being met. In addition to resilience, caregiver status and avoidant coping contributed to perceived stress. As well as perceived stress, family support, social support and benefit finding contributed to resilience.

There were no significant contributory factors identified for variance in hair cortisol, social support did not act as a moderator of perceived stress on hair cortisol.

Conclusions: This programme of research identified a number of potential protective resilience factors in a population of young carers, contributing to an area of literature previously unexplored. The findings of this research support the transactional model of stress and coping, and offer substantial evidence for the relevance and applicability of the socioeconomic model of resilience in young carers. The use of physiological assessment in the form of hair cortisol concentration adds to the general psychoneuroendocrine literature and further develops the stance of immunosenescence in carers. The research makes methodological contributions and provides a basis for both future research with young carers and the development of stress resilience interventions, whereby the factors identified in this work can be harnessed to promote positive outcomes.

List of abbreviations

ACTH: Adrenocorticotrophic hormone

AD: Alzheimer's Disease

ADHD: Attention Deficit Hyperactivity Disorder

AIDS: Acquired immune deficiency syndrome

ASD: Autism Spectrum Disorder

BBC: British Broadcasting Company

BEST-C: Bath experimental stress test for children

BFSC: Benefit Finding Scale for Children

BFCCS: Benefit Finding in Child Caregivers Scale

CAR: Cortisol Awakening Response

COPD: Chronic Obstructive Pulmonary Disease

CRF: Corticotrophin releasing factor

CYRM-28: Child and Youth Resilience Measure – 28

DBS: Disclosure Barring Service

DHEA: Dehydroepiandrosterone

DoE: Department of Education

DoH: Department of Health

GAS: General Adaptation Syndrome

HIV: Human Immunodeficiency Virus

HPA: Hypothalamic-pituitary-adrenal

IL: Interleukin

JB: Julie Barnett

JTC: Julie Turner-Cobb

IPA: Interpretative Phenomenological Analysis

MC: Matched control

MDI: Multiple Deprivation Index

MS: Multiple Sclerosis

NK: Natural Killer

ONS: Office of National Statistics

PNE: Psychoneuroendocrinology

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

PSS-10: Perceived Stress Scale – 10

PSS-Fr: Perceived Social Support from Friends

RA: Rheumatoid Arthritis

SAM: Sympathetic Adrenomedullary System

SD: Standard Deviation

SPSS: Statistical Package for the Social Sciences

SRRS: Social Readjustment Rating Scale for Teens

TA: Thematic Analysis

TH: Tamsyn Hawken

UK: United Kingdom

USA: United States of America

WFSI: Wills Family Support Inventory

YC: Young Carer

YCPSS: Young Carers Perceived Stress Scale

Chapter one: Introduction

1.1 Chapter overview

This chapter provides a brief overview of the research topic, psychophysiological outcomes and resilience in young carers. Relevant statistics, context and political stances surrounding young carers are presented. The key research approaches and academic disciplines within this programme of research are described alongside definitions of the key terms used throughout, including stress, resilience and young carers. Finally, the research aims, objectives and questions are presented in addition to an overview of the thesis structure.

1.2 The experiences of young carers: towards an understanding of psychophysiological resilience

Approximately 6.5 million people in the United Kingdom (UK) are an unpaid carer (Office for National Statistics; ONS, 2011) providing between one and more than 50 hours of care per week, with an average of 24.4 hours (Revenson et al., 2016). Whilst healthcare improvements and innovations enable many physical and mental health conditions to be managed at home, this often requires family members or friends to become carers (Schubart, Kinzie, & Farace, 2008). Carers can be any age and they may provide domestic care, general care, personal aid and emotional support (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006).

Due to variations in defining young carers (Pakenham et al., 2006) and the challenging nature of identifying them, it is difficult for researchers and governments to accurately estimate the proportion of young people who adopt a caregiving role. Lloyd (2013) argues that figures from national surveys and censuses are unlikely to provide a true representation of the extent of young carers, predominantly because census data requires self-declaration of carer status and many do not identify, or wish to be identified, as a young carer. Despite this however, the ONS publication of the 2011 census survey in May 2013 found that there were 177,918 young unpaid carers between the ages of five and 17 years old in England and Wales, and Nagl-Cupal, Daniel, Koller and Mayer (2014) found that as the age of young people increased, as did the proportion of individuals providing care. Of the young carers identified in the census, the numbers of males and females providing care were similar, with 54% girls, and 46% boys. Within England and Wales, most young carers (80%) provided between one and 19 hours of care per week which is similar to carers in other age groups. A further 11% provided between 20 and 49 hours and 9% provided 50 or more hours per week.

Nagl-Cupal, Daniel, Koller and Mayer (2014) highlighted that carers can be identified in every social class and the most common scenario was young carers providing care for their mother (Kavanaugh, 2014). The census findings indicated that the number of individuals reporting their health as ‘not good’ was higher in those providing care than those who were not. Results from the 2011 census provide an estimation of the extent of youth caring in England and

Wales, however some argue that due to their hidden nature, young carer statistics are unlikely to be accurate and therefore are an underestimation of the true extent of caregiving (Pakenham et al., 2006). Indeed the BBC, in collaboration with The Princess Royal Trust for Carers (2010) conducted a poll of 4,029 children from ten UK secondary schools and found that one in 12 (8%) had provided informal care in the previous month. Two hundred and sixty of these young people stated they providing care "some of the time" whilst 77 provided care "a lot of the time". The survey found different results to that of the census regarding gender distribution, with 226 girls (67%) and 111 boys (33%) providing care. Howatson-Jones and Coren (2013) highlight that if this poll were to be representative of the UK as a whole, it could suggest that there are approximately 700,000 young carers within the population, around four times more than the 2011 census identified. The DoH (Department of Health; 2010) emphasises that many young carers are not identified and The Royal College of General Practitioners (2013) note that it is entirely possible that an even larger number of young people may be providing informal care than initially thought.

There are a number of reasons why a young person may become a carer. Life expectancies and ageing are increasing globally which places pressure upon health and social care services in order for them to maintain a sufficient level of support and adapt to changes (Kuuppelomäki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004). Increasingly, services are being provided on an outpatient basis, this is particularly true of mental health care, and places caring responsibility upon family and friends who live with or interact with, the unwell individual (Ali, Krevers, & Skarsater, 2015). The most common instances in which young people become carers is in single parent families or when both parents in the family are ill. There are also situations whereby the well parent is required to work to maintain income or because other family members are not available to provide support and care (Thomas et al., 2003). Day (2015) states that when family members become ill or are managing a long term health condition they require care that is immediate, accommodating and ongoing, and often they look to their children or partners to meet these needs.

Therefore, the development of a caring role is often due to necessity and a lack of other options and can be a gradual process in which more caregiving responsibilities are adopted over time. Hamilton and Adamson (2013) identified that young carers found it difficult to explain when their caregiving role began, and this is reflected in qualitative findings from Rose and Cohen (2010) whereby young carers were often unable to identify how or why they had become carers. Nagl-Cupal, Daniel, Koller and Mayer (2014) suggest that adopting a carer role as a young person can be motivated by a desire to maintain the family unit and live as ordinarily as possible. Furthermore, young people may feel they have no choice and are required to become the 'man of the house' and try to compensate for an absent parent (Aldridge & Becker, 1999).

There are clear variations in the nature of young carers, however there is general agreement that although specific responsibilities are determined by the type of illness, the tasks

carried out by young carers are often complex and would typically be associated with the duties of an adult carer (Nagl-Cupal et al., 2014). Pakenham et al (2006) summarised five areas in which young carers provide support and later Simon and Slatcher (2011) presented statistics on how many young carers provide them (totals do not equal 100% due to many young carers providing multiple forms of care). The areas include domestic care tasks such as cooking, cleaning and shopping (68%), general care such as planning, managing finances and giving medication (48%), personal or intimate care such as toileting, showering and bathing (18%), emotional support including comforting and monitoring a parent's mental state (82%) and child care for siblings (11%).

1.2.1 Political context

In recent years the population defined as young carers has been increasingly acknowledged in a number of areas, including policy, social services and research (Hamilton & Adamson, 2013). There is, however, an ongoing debate within the informal carer literature that highlights controversy surrounding the nature of young carer roles. Aldridge and Becker (1999) state that despite intervention in the form of health and social care services, when a family member becomes unwell, it is probable that children will take on caring responsibilities at some level. A conflict has arisen between the disability rights of an individual with an illness and the rights of the young carer as a minor. The question has been raised as to whether young carers should be supported by services to continue in their role or whether the individual receiving care should be further supported to reduce the responsibility placed upon the child (Thomas et al., 2003). Aldridge and Becker (1999) argue that even when support such as physical assistance is provided to individuals with illness, it is likely that a young carer will still be required to provide emotional support, and therefore will act as and experience themselves as carers.

There is also a wider argument surrounding public funding and cuts to budgets for services such as adult social care which have occurred in recent years and have necessitated an increase in informal carers providing care to those with an illness or disability. A 2015 report (Buckner & Yeandle) found that the amount of home care provided by local authorities had decreased by 4.3% between 2011 and 2014, with an estimated total funding gap between those needing care and local authority budgets of £700 million a year. The report concludes that individuals are increasingly becoming informal carers in order to address this gap with the carer population in the UK increasing by 16.5% from 2001 to 2015, saving the state an estimated £132 billion a year (Buckner & Yeandle, 2015). Carers UK (Press release; November, 2015) argue that informal carers are caring "against a backdrop of cuts to social security and local care services" and the lack of support available for this population is decreasing, making informal caregiving "dangerously unsustainable".

More recently, the Association of Directors of Adult Social Services conducted a budget survey (June, 2019) which prompted Carers UK to release a statement advocating for the

government to not only put in place funding to address the lack of formal care provided to those experiencing illness or disability, but also to provide "high quality and affordable care and access to the breaks and support carers need for their own health and financial security". Returning to the conflict surrounding the disability rights of an individual with an illness, and the rights of carers, this statement indicates that support is needed for both parties, and that support for an informal carer is indirectly supportive of an individual receiving care, and vice versa. Though steps need to be taken to address the lack of formal care and the overall health care system, the provision of support and services to those providing informal care is also paramount, whereby research in the area can lead to evidence based and economical carer interventions.

1.3 Key research approaches and academic disciplines

The programme of research presented within this thesis involves various approaches and academic disciplines, in particular, the nature of the research is predominantly placed within child health psychology, however it incorporates elements of a life course perspective and the field of psychoneuroendocrinology (PNE).

Child health psychology is defined as "the specific application of health psychology research and practice to physical health in children, as well as the implications and applications of psychosocial influences during childhood development on subsequent health in adulthood" (Turner-Cobb, 2013, pg4). The current research applies health psychology theory and methods to a specific youth population, young carers, to establish the implications of caregiving on their biopsychosocial health. Furthermore, the present research adopts a lifespan perspective, whereby there exists a longer term aim to harness protective resilience factors that may facilitate positive outcomes and thus prevent the detrimental impacts of caregiving as a young person extending into adulthood. Additionally, research surrounding psychophysiological outcomes in young carers is lacking, and thus a true lifespan perspective regarding the psychophysiological impacts of caregiving cannot exist.

Finally, due to the physiological measurement of a stress biomarker, this programme of research incorporates PNE, a field of research which "represents an interdisciplinary approach to integrating basic findings from several research disciplines" and "is aimed at elucidating endocrine [hormonal] functions and their dysfunctions" (Campeau, Day, Helmreich, Kollack-Walker, & Watson, 1998, pg259). A reciprocal connection between psychological factors, hormonal function and nervous system activation exists, which can also impact immune function and overall risk of disease (Turner-Cobb, 2013). The stress biomarker measured in the current research, cortisol, is a hormone and is assessed alongside psychosocial factors as a consequence of stress, a response that takes places within the nervous system. By utilising and combining these areas of research, the current programme incorporates the discipline of PNE.

1.4 Defining stress, resilience and young carers

This chapter will now provide definitions for the key terms used throughout this thesis, alongside a definition of a 'young carer'.

1.4.1 Stress

The definition of stress has been debated and considered from numerous stances, however a typical understanding of the concept is that stress occurs when an individual perceives the demands of a situation to be greater than the resources they have available to effectively cope (Lazarus & Folkman, 1984). Sarafino (1998) later expanded this definition and added that resources are drawn from biological, psychological or social systems, and the perceived imbalance between these and the demands of a situation need not be true in order to result in stress. Dhabhar (2013) has further defined stress as a sequence of events involving three aspects. Initially, a stimulus or stressor causes a reaction in the brain, after which stress perception occurs, which in turn triggers the physiological stress response in the body. Stress can be considered acute or chronic and is typically differentiated based on the duration and intensity of the stressor. Acute stress involves a stressor that lasts for a relatively short period of time, such as minutes, hours or days and causes the stress response to be activated for short lengths of time. Chronic stress (such as caregiving) on the other hand is more persistent, and can last weeks, months or years and leads to repeated activation of the stress response during this time (Gottlieb, 1997).

1.4.2 Resilience

The concept of resilience is notoriously difficult to define, with little agreement on an operationalisation of the concept (Gaugler, Kane, & Newcomer, 2007). However, a number of researchers have sought to do so. For the most part there is some agreement about resilience; that it is a factor involved in stress coping ability (Connor & Davidson, 2003), it may represent the "ability to bend not break" when under pressure or stress (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014, pg2) and for resilience to develop, an individual must encounter a risk factor and it is the presence of protective factors which promote resilience (Garmezy, 1987; Luthar, Cicchetti, & Becker, 2000; Rutter, 1979; Werner & Smith, 1982). These researchers also suggest that being resilient goes beyond coping with difficult circumstances and is perhaps a step from surviving to thriving.

Connor and Davidson (2003) argue that the concept of resilience is multidimensional and encapsulates the personal qualities and characteristics that enable a person to overcome challenges. Windle, Bennett and Noyes (2011, pg2) on the other hand view resilience as "a process of negotiating, managing and adapting to significant sources of stress or trauma". Finally, Luthar et al (2000, pg547) define resilience as "a dynamic process encompassing positive adaptation within the context of significant adversity". In line with Rutter (1979) and

Windle et al (2011), Luthar et al argue resilience results from an interaction between an individual's internal assets and environmental resources, a perspective that is supported by Southwick et al (2014) who argue that resilience involves biological, psychological, social and cultural factors, and it is an interaction of these factors which determines how an individual will adjust to any difficulties they are faced with.

Therefore, most researchers and theorists argue that multiple systems are involved in resilience and no single feature of an individual or environment can solely predict it. Furthermore, for Southwick and colleagues (2014), resilience exists on a continuum, where in some instances individuals demonstrate greater resilience and in other instances less so, for example in different situations or at different ages.

Richardson et al (1990) suggest that there are four possible outcomes when individuals are faced with a stressful or traumatic situation to which they have to respond. In all cases, the starting point is one of biopsychosocial balance whereby an individual is able to adapt to their ever-changing environment and life circumstances. However, when challenged by a stressful encounter, the way in which an individual responds will determine whether they (1) recover with increased resilience and improved balance, (2) recover and return to a previous state of balance, (3) recover but experience a loss of balance or (4) reach a dysfunctional state due to using coping strategies that are maladaptive. Those who demonstrate resilience typically experience a temporary state of unbalance but eventually return to a healthy point, following the use of effective and adaptive coping strategies (Southwick et al., 2014).

In 2011, Windle, Bennett and Noyes conducted a methodological review of scales used to measure resilience. They highlighted that these measures, and indeed resilience theory itself, had been developed as the result of dissatisfaction with 'deficit' models, that is, those that focus on factors which can lead to negative rather than positive outcomes. Zimmerman (2013) describes resilience as a strengths based approach which allows the focus to remain on factors that can positively influence the course of development or adjustment following exposure to a stressor and help individuals overcome difficult circumstances. This is reflected by Southwick et al (2014) who highlight that researchers are beginning to consider what goes right rather than what goes wrong.

1.4.3 Young carers

Informal carers are typically defined as those who provide unpaid care for individuals, such as family members or significant others, who cannot take care of themselves due to chronic illness, disability, a mental health condition or the effects of aging such as increased fragility (Kuster & Merkle, 2004; Lloyd, 2013). Carers characteristically provide care for extended periods of time (e.g. beyond that of an acute condition which may last weeks or months) which often involves a high level of emotional and psychological involvement (Day, 2015).

Although carers are clearly defined, the task of defining young carers is described as controversial and complex (Thomas et al., 2003). Rose and Cohen (2010) argue that there is no agreement on the definition of a young carer and that determining what is considered a 'normal' childhood and what makes an individual a young carer is very difficult. Walmsley (1993) views care on a continuum, whereby caring for and about other people is a feature of most children's lives and is typically encouraged. Indeed, Aldridge and Becker (1999) state that young people are encouraged to care for others during their childhood and that this can be a healthy part of their development. Young carers however, are viewed as providing levels and types of support that are beyond that which is usually seen in young people. Therefore, young carers are defined depending on the level and intensity of the caregiving responsibilities that they have (Pakenham et al., 2006). The DoH defines young carers as "children who are providing or intending to provide a substantial amount of care on a regular basis", this is opposed to non-young carers who may offer short term support to a family member who has an acute illness or injury (Nagl-Cupal et al., 2014). Despite the complexity associated with defining young carers, Becker (2000, pg378) has defined them as "children or young persons under 18 who provide, or intend to provide care, assistance or support to another family member" and who "carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would normally be associated with an adult". Becker (2007) later added the dimension of time to the definition, stating that in general, care is provided on a long term basis.

Partly due to the uncertain definition of young carers, identifying these individuals within society has been considered a "difficult and sometimes impossible task" (Stamatopoulos, 2015, pg811). However, other barriers exist and contribute to the challenge of identifying young carers. Research has found that many young carers express the need to protect themselves and their families (Rose & Cohen, 2010). Thomas et al (2003) highlights that the term young carer can pose a threat to individuals receiving care, as it can place them in a position of reliance and incompetence. In particular, many young carers express fear that their parent will be determined as inadequate and they will then be separated by social services and taken into care (Frank, 1995). Some young carers also describe keeping their caregiving a secret because they fear they may be judged, criticised or over-examined by services and may be subjected to unsolicited advice, intervention or intrusion (Nagl-Cupal et al., 2014; Rose & Cohen, 2010; Thomas et al., 2003). There is also an issue of perception and normality that surrounds the role of caring in young people. Svanberg, Stott and Spector (2010) describe participants in their qualitative research as disagreeing with being identified as a young carer as they believed their responsibilities and role were a case of 'just helping'. Nagl-Cupal et al (2014) argue that young people with a caregiving role may not consider themselves to be or define themselves as a young carer as the support they provide is a normal and everyday part of their life. Overall, the profile of young carers is low and this leads to difficulties identifying them individually

(Thomas et al., 2003) but also the degree to which young carers as a whole are providing care (Day, 2015).

1.5 Aims, research questions and objectives of the research

The overall aim of this programme of research was to explore the mechanisms underlying psychophysiological resilience in a young carers, specifically, aiming to identify factors which may contribute to outcomes in this population. Therefore, the research questions investigated were:

1. What factors contribute to resilience and psychophysiological adjustment in general informal carer populations?
2. Are resilience factors identified in the general informal carer population the same or different in a young carer population?
3. What factors contribute to perceived stress, resilience and physiological outcomes in young carers?
4. Do young carers and young non-carers report similar or different psychophysiological stress profiles?

The main objective of study one was to conduct a systematic review of the caregiving literature surrounding coping and adjustment, identifying factors that contribute to both positive and negative outcomes in an informal carer population. The purpose of this study was to gain an overall understanding of research conducted thus far, and to provide a basis upon which to conduct young carer research.

The main objective of study two was to conduct a qualitative study to further explore factors identified within the systematic review and a general informal caring population to determine whether these factors were relevant to a population of young carers. A further objective was to also investigate additional factors that may be present in young carers' lives and contribute to positive or negative adjustment. Data were collected through in-depth semi-structured interviews using auto-driven photo elicitation.

The primary objective of study three was to conduct a quantitative study utilising questionnaires and a physiological measure of stress (hair cortisol concentration) in a non-invasive manner, to statistically determine factors that contribute to specific outcomes in young carers. The secondary objective was to also collect data from a population of age and gender matched non-carers to compare the psychophysiological stress profiles of this group to young carers.

1.6 Structure of the thesis

1.6.1 Chapter one: Introduction

As described at the start of this chapter, the research area has been presented alongside information such as young carer statistics and political context. The key research approaches, disciplines and definitions have been discussed and the study aims, objectives and research questions have been provided. This chapter will now provide a brief overview of the contents of each chapter in the thesis.

1.6.2 Chapter two: Literature review

The literature review chapter provides an overview of stress physiology and theories and models of stress and resilience. Informal caregiving is presented as a risk factor and the outcomes of caring on elderly, adult and young carer populations are discussed. Psychosocial factors impacting carer outcomes are presented including coping, social support, benefit finding and resilience.

1.6.3 Chapter three: Methodology

The methodology chapter begins with a brief history of young carer research and provides an overview of the epistemologies, research designs and the analytical approaches relevant to the current programme of research. Methods for assessing stress and psychosocial factors are discussed and rationale for methodological and perspective decisions are given. Justification of a mixed methods approach is provided and the typology and analytic strategy are presented. This chapter ends with discussion of the challenges surrounding research with children and young carers, including ethical considerations.

1.6.4 Chapter four: Study one

Chapter four presents a detailed account of the process undertaken to conduct a systematic review to assess coping and adjustment in general informal carers. PRISMA guidelines were followed to ensure rigour and quality. A rationale for the systematic review is given, a detailed method is provided and the findings of the study are presented. Findings are discussed, alongside methodological issues, strengths and limitations of the systematic review literature and the systematic review itself, alongside future research recommendations.

1.6.5 Chapter five: Study two

Chapter five presents the first empirical study of this programme of research, a qualitative study using auto-driven photo elicitation to explore factors that may enable coping and resilience in a population of young carers. Background is presented including the use of the socioecological framework of resilience as a guiding model in this study. Justification for the

method used and details surrounding the thematic analysis are provided. Themes are presented and illustrated with quotes and relevant photographs taken by young carers where appropriate. Finally the findings are discussed in relation to previous literature and their applicability to the socioeconomic framework of resilience. Strengths, limitations and applications are presented in the discussion section of this chapter.

1.6.6 Chapter six: Study three

Chapter six presents the second empirical study of this programme of research, a quantitative study utilising questionnaires to measure psychosocial factors and hair samples to assess hair cortisol concentration in a sample of young carers and age-gender matched non-carer controls. The study builds upon the culmination of the literature review, systematic review and interview study. Statistical analyses were conducted and these are presented in the chapter. Discussion of these findings is presented with consideration of past literature and the strengths and limitations of the study.

1.6.7 Chapter seven: Overall discussion

The final chapter in this thesis presents an overview of the results from each of the studies, in relation to the research questions, previous literature, theory and applications. Strengths, limitations and suggestions for future research are provided and this chapter ends with the main conclusion.

Chapter two: Literature review

2.1 Chapter overview

This chapter will begin by outlining the physiology of stress and will present the main theories and models of stress, including General Adaptation Syndrome, the Transactional Model of Stress and Coping, and Allostatic Load. The development of theories of resilience will then be discussed and applied to informal caring which is conceptualised as a risk factor in the context of resilience. The psychosocial and physiological impacts of caregiving, both positive and negative, will be discussed in relation to adult and elderly carers and young carers. Finally, factors that impact carer outcomes, including coping, social support, benefit finding and resilience will be discussed.

2.2 Stress physiology

When an individual encounters a stressor, a stress response is activated within the body. Although over time, with repeated activation, the stress response can become damaging, it is inherently an adaptive survival mechanism that prepares the body and immune system for any possible challenge or injury that may arise as a result of a stressor (Dhabhar, 2013). The human stress response is a two-fold system which involves the sympathetic adrenomedullary (SAM) system and the hypothalamic-pituitary-adrenal (HPA) axis. These parts of the stress response are activated at different times in relation to the perception of a stressor, with the SAM system triggered at the point of perception and the HPA axis activated approximately 20 minutes after (Conrad, 2011). When a stressor is perceived the sympathetic nervous system is activated which stimulates the adrenal medulla and results in the production of adrenaline and noradrenaline. This process is responsible for the 'fight or flight' response, whereby the body experiences a number of physiological changes that enables all resources to be directed to overcoming the stressor it is faced with. These changes include increased energy, increased alertness, greater blood flow to muscles, higher heart rate and reduced activity of the digestive system. This aspect of the stress response is relatively short lived, however the HPA axis is also activated. When the stressor is perceived the hypothalamus releases a hormone called corticotrophin releasing factor (CRF) which in turn stimulates the anterior pituitary gland in the brain which secretes adrenocorticotrophic hormone (ACTH) which travels through the blood stream and reaches the adrenal cortex, whereby the release of cortisol is triggered. This part of the stress response allows the body to maintain a steady supply of glucose for energy and is also responsible for the suppression of the immune system and anti-inflammatory action (Conrad, 2011). When the stressor is no longer present or an immediate threat, the hypothalamus receives this feedback and the body returns to its pre-stress baseline. In acutely stressful situations (lasting for minutes, hours or days) levels of cortisol and other hormones secreted during the stress response can strengthen the immune system and typically return to baseline levels within

approximately 30 minutes. In chronic stress situations however (lasting weeks, months or years), the stress response is repeatedly activated leading to cortisol levels that remain raised, leading to a dysregulated HPA axis which in turn can cause down regulation of the immune response (Lovell & Wetherell, 2011). Dysregulation of the HPA axis, alongside other stress hormones has been widely linked to health conditions and adverse health outcomes, predominantly as a result of impaired immune functioning (Slatcher et al., 2015).

2.3 Theories and models of stress

Three theories of stress will now be discussed, General Adaptation Syndrome, the Transactional model of stress and coping, and finally allostatic load. Each theory presents an explanation for how stress can negatively impact individuals on a biopsychosocial level.

2.3.1 General Adaptation Syndrome (GAS)

The early theories of stress such as General Adaptation Syndrome (GAS; Selye, 1950, 1976) characterised the stress response into three parts. The first, is the alarm stage, where a stressor is consciously detected and categorised as a challenge. The second is the adaptation (or resistance) stage, where the body attempts to maintain balance of the physiological systems in the face of the stressor. The final stage is exhaustion, which typically occurs as a result of chronic or prolonged stress, when the body's capability to adapt to stress is depleted. It is in this final stage where physiological balance can no longer be maintained and stress related illness or disease may occur. Some researchers have challenged the idea that the stress response may become depleted, and argue that rather than the response becoming exhausted, the repeated release of stress hormones becomes damaging to health (Sapolsky, 2007).

2.3.2 Transactional model of stress and coping

Moving on from GAS, theories of stress focussed more on the individual and their environment, rather than the stressor itself. In the transactional model of stress (Lazarus & Folkman, 1984), stress is viewed as an ongoing and interactive process whereby the individual and their environment interact (Sarafino, 1998). The transaction, or interaction, occurs when an individual conducts two evaluations, first of the impact of the stressor (primary appraisal) and second, of the coping resources an individual has available to deal with the stressor (secondary appraisal). It is when there is a perceived deficit in the resources required to cope with a challenging situation that stress becomes the outcome. Ultimately, the experience of stress is based on a system of appraisal, response and adaptation in which reappraisal can also occur after coping resources are initially used and a situation requires revaluation (Lazarus & Folkman, 1984).

Within the transactional model of stress, two forms of coping are specified, problem-focussed and emotion-focussed. The former includes strategies which seek to deal with or

actively change a situation whereby the latter seeks to change the relationship between the stressor and how it is experienced, for example through denial, avoidance or cognitively reframing a situation (Lazarus & Folkman, 1984). Maladaptive coping strategies are typically those that reduce the experience of stress in the short term, but do little to help, or alternatively exacerbate the problem in the long term. Adaptive coping strategies on the other hand enable an individual to manage their stress in the long term and have the capacity to lead to resilience by equipping individuals with resources for managing future stressors (Lazarus & Folkman, 1984).

2.3.3 Allostatic load

Researchers investigating the physiological impact of stress frequently apply allostatic load (McEwen, 1998) as the mechanism through which stress can lead to the dysregulation of multiple organ systems within the body including the endocrine, metabolic, cardiovascular, respiratory, immune and anthropometric systems.

According to allostatic load theory, the body is in a continuous process of maintaining stability (allostasis), particularly when experiencing changes or physiological disruptions such as those associated with the stress response (McEwen, 1998; Sterling & Eyer, 1988). In the short term, this process of the body seeking balance and restabilising the physiological systems involved in the stress response, enables adaptation to challenges. However, in the long term, when the stress response is repeatedly activated or negative lifestyle factors also contribute, the body is unable to maintain balance and physiological systems become dysregulated, thus resulting in allostatic load which can lead to negative health consequences and poor health (Sapolsky, 2007). This is described as the stress response not becoming entirely depleted, but becoming damaging towards the body (Sapolsky, 2007). Allostatic load is a measurable indicator of physiological health in relation to stress and is determined by assessing a number of biological markers which will be discussed in the next chapter.

2.4 Resilience theory

A number of theories exist surrounding resilience, each with varying definitions of the concept and suggesting a number of ways in which it develops and operates.

2.4.1 Resilience as an interactive process

One of the first theorists to discuss resilience was Rutter (1979) who has since defined the concept as "interactive…that is concerned with the combination of serious risk experiences and a relatively positive psychological outcome despite those experiences" (Rutter, 2006, pg3). Like more modern theorists (E.g. Southwick et al, 2014), Rutter argues that resilience is not related to personal psychological traits nor is it a demonstration of greater functioning than those who do not demonstrate resilience. Rutter suggests that resilience operates across the lifespan, not unlike Southwick and colleagues' suggestion of a resilience continuum, on which

different types of risks and the environment in which they are experienced can influence resilience, or the lack thereof. The importance of individual differences however, is not neglected and Rutter acknowledges that factors such as genetics, personality and temperament interact to impact how people respond to challenging situations. Luthar et al (2000, pg543) also offers a process based definition of resilience whereby it is "a dynamic process encompassing positive adaptation within the context of significant adversity". In particular, resilience requires the exposure to a factor that poses a threat or some form of adversity to which an individual can then respond positively and adapt to their challenging circumstances. Luthar does not regard resilience to be a unique individual trait, but similarly to Rutter argues that resilience is the result of an interaction between an individual and the environment in which they are experiencing stress or adversity.

2.4.2. Resilience as individual capacity

Werner and Smith (1982, pg4) define resilience as the capacity that an individual has to "cope effectively with the internal stresses of their vulnerability and external stresses" this is in contrast to theorists presented above, but in line with Masten (2001) who defines resilience as the capacity of a dynamic system to adapt successfully to disturbances that threaten system function, viability or development. Masten's approach is described as person-focussed, whereby it takes into account the whole individual and typically compares resilient and non-resilient people to understand how they are different and what protective factors may be operational to enhance resilience.

2.4.3 Risk factors and protective factors

Challenging situations, or those that introduce the possibility of negative outcomes and consequences, are called risk factors (Rutter, 2006). Risk factors in young people can include severe parental marital discord, low socioeconomic status (SES), an overcrowded or large family and parental criminality or psychiatric disorder. It is an individual's unique situation that presents risk factors, however there are also a number of factors than can promote resilience and these are named protective factors, that is, protective against the potential negative impact of exposure to a risk factor.

Protective factors as described by Rutter include cognitive characteristics such as planning, self-control, self-reflection, sense of agency, self-confidence and determination. The importance of social support and relationships are also emphasised, with factors such as maternal warmth, sibling warmth and a positive family atmosphere cited as having a protective and positive impact on young people after experiencing stress or trauma (Rutter, 1979). Furthermore, examples of community factors include professional tangible support, health care and wider social support from friends. Luthar and Brown (2007, pg949) highlight that

relationships are of great importance within resilience work and argues that they "lie at the root of resilience".

In Luthar's resilience theory three types of protective factors are outlined, these include protective stabilising, whereby the factor provides stability despite the presence and increase of stress or risk; protective enhancing, whereby an individual can experience stress but is able to increase competence as a result and finally, protective but reactive, whereby stress provides an opportunity for the development of increased competence, but only if the stress is not of a high level.

Despite providing some examples of protective factors, Rutter clarifies that lists of risk and protective factors are able to generate a general picture of resiliency factors, but cannot provide context or specific details with regard to individual differences. Similarly, Luthar et al (2000) argue that the categorisation of protective and risk factors is not particularly intuitive, and that factors which could be considered protective may in fact pose a risk, whilst factors typically perceived as a risk may in fact be protective. Much like Connor and Davidson (2003), Luthar posits that resilience is a multidimensional concept and similarly to Southwick et al (2014) theorises that individuals can demonstrate resilience in some areas but fail to be resilient in others.

Though most definitions of resilience focus upon psychological outcomes, Rutter's work (1979; 2006) does discuss the potential impact of biological and genetic influences within risk and protective factors. He argues that biological factors such as genetics or early life adversity can hamper coping efforts due to the potentially damaging effect on neural structures. Rutter calls for further research within this area and for a stronger focus on the biological aspects of risk and resilience.

2.4.4 The social ecology of resilience

Garmezy (1991, pg465) states that the term resilience reflects "the capacity for recovery and maintained adaptive behaviour that may follow initial retreat or incapacity upon initiating a stressful event". Garmezy takes an socioecological view of resilience whereby protective factors operate on three levels; individual, familial and general support, the latter of which is external to the family and may include teachers, social workers or friends. In Garmezy's explanation of resilience there are three main models. The first is the compensatory model, which is considered an additive model, where the impact of stress can decrease general competence but personal qualities can enable positive adjustment. The second model is a protective versus vulnerability model which similarly to Rutter, suggests that there is an interactive relationship between both stressors and personal attributes, which determines the extent to which someone is able to adapt and thus demonstrate resilience. Finally, the third model is the challenge model, which represents a curvilinear relationship between stress and positive outcomes, whereby stress enhances adjustment through the challenge of the coping strategies an individual has. It is

important to note however that like the eustress model, very low or very high levels of stress are unlikely to lead to positive adjustment.

Other theorists also categorise protective factors into groups or levels within an ecological or socioecological model including Werner and Smith (1982) and Masten (2001, 2011), who classify protective factors on individual, family and community levels. Werner and Smith suggest that these factors can influence resilience both directly and indirectly, for example support from a professional service may make it possible for a parent to be emotionally available to their offspring. Furthermore, Werner's theory of resilience posits that the more stress or risk factors that an individual is exposed to, the more protective factors that are required to facilitate resilience and adaptive coping.

Windle and Bennett (2011) proposed a theoretical model of resilience for informal carers, specifically applied to carers of spouses with dementia (see figure 2.1 below) and argued that carers depend on individual assets to manage their situation, but also that they interact with their environment through social and community resources. These resources can act as protective factors against the risk factor of their caregiving and their absence can lead to further challenges or poor well-being.

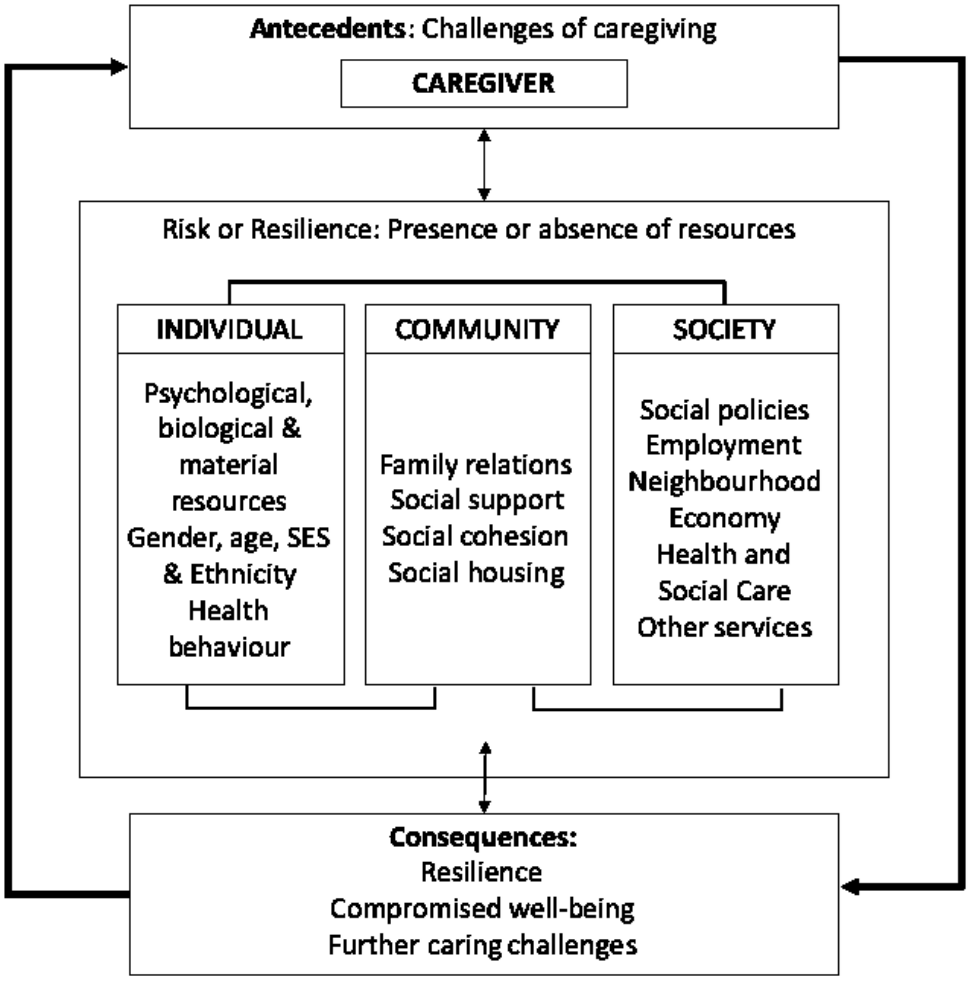

Figure 2.1 Adaptation of Windle and Bennett's (2011) theoretical model of resilience for carers

2.4.5 Common factors within theories

Though there have been many contributions to resilience theory, there are a number of similarities between the various offerings of researchers. Firstly, though some theorists discussed above suggest that resilience is a quality or capacity that an individual has, they all agree that resilience is the result of an interaction between an individual and their surrounding environment. Secondly, all of the definitions of resilience provided by theorists are based on the premise that an individual needs to experience a risk or stressful situation and consequently manage this situation in a positive way, demonstrating affective adaptation. Alongside this, all theorists draw on the notion that resilience involves the presence of protective factors. Thirdly, all theorists conceptualise these protective factors at three levels, including the individual, the family and the community/environment. Fourthly, most theorists concur that risk factors and protective factors are specific to individuals and their unique environments and finally that an accumulation of risk factors is more detrimental than an individual risk, however exposure to risk factors is not always damaging provided they are within a controllable range.

2.5 Caregiving as a risk factor

Advances in healthcare and medicine in recent decades has enabled more effective management of long term health conditions (Pakenham & Cox, 2014) subsequently the number of individuals living with a chronic illness is increasing. The Department of Health reported in 2012 that approximately 15 million people in England had a long term health condition, defined as a "condition that cannot, at present, be cured but is controlled by medication and/or health and social care services". As a result, more children and young people are required to grow up and develop in a situation that is challenging and difficult, in which a parent, sibling or other close relative is managing a chronic or long term health condition (Rolland, 1999).

Research has demonstrated that living with a parent with a physical or mental health condition can be detrimental to a child's psychosocial wellbeing and adjustment. Within a family, there is potential for each member to be affected in some way by the presence of a health condition (Day, 2015) and for young people in particular, parental illness can be a considerable challenge (Ireland & Pakenham, 2010), even if they do not provide informal care. A number of difficulties that young people living with parental illness may experience have been identified (Barnett & Parker 1998). As a result of their parents' condition, whether providing care or not, children may find themselves subjected to stigma from peers and being used as an interpreter in medical situations. Fear is also a factor associated with parental illness, whereby there are concerns for the future and of developing the same condition. In addition, restrictions on young peoples' social lives, lack of familial communication and a lack of parental guidance have been identified as difficulties experienced in the face of parental illness. A number of studies have concluded that children and adolescents from families with

chronically ill parents are at a higher risk of displaying stress symptoms, low self-esteem, poor educational performance and developing conditions such as anxiety or depression (Faulkner & Davey, 2002; Ireland & Pakenham, 2010; Sieh, Visser-Meily, Oort, & Meijer, 2012). Children of parents with a mental health condition have been highlighted as especially at risk of long term consequences, specifically those associated with depression and anxiety, such as insomnia, sadness, lack of appetite, relationship difficulties and educational problems (Thomas et al., 2003).

Some research has compared children of healthy families to those who have a parent or other relative who is unwell and found that children within a family where a relative has an illness are at greater risk of developing their own mental health difficulties, compared to young people from a healthy family. In addition, when the relative with the illness is a parent, the risk is significantly increased (Pakenham & Cox, 2014).

It is evident that growing up within a family where a relative has any type of health condition can be damaging and have a negative impact upon the health and well-being of young people, however a great deal of the current research in this area fails to recognise the role of caregiving (Pakenham & Cox, 2014). In some cases, when a family member is suffering from a chronic or recurrent health condition, professional support and care is provided. However in many instances the responsibilities of care fall upon informal carers such as friends and relatives (Finch, Finch, & Mason, 2003). Children living with a relative with an illness are often required to take on caregiving roles, which may include caring for their parent or a sibling (Pakenham & Cox, 2014a) and Aldridge and Becker (1999) highlight that it is difficult to calculate the number of children who adopt caregiving responsibility within their family.

It is this evidence that enables informal caring to be considered a risk factor, and thus a life experience that requires effective coping and protective factors in order to maintain balance, both psychologically and physiologically.

Despite the evidence for negative impacts, as previously discussed, not all informal carers experience detrimental outcomes and some demonstrate high levels of adaptive coping and resilience. Therefore, resilience theory would suggest that there are protective factors at play, enabling carers to overcome the stresses of their role. Indeed, a small number of studies have begun to investigate factors within a carer population that may promote resilience and positive adjustment outcomes.

2.6 Impacts on adult and elderly carers

The literature surrounding adult and elderly carers provides an insight into the nature of caregiving and the potential impact it can have upon health and psychosocial well-being.

2.6.1 Psychosocial outcomes

The vast majority of the literature suggests that many carers report the negative impact of caregiving upon their health and well-being, however it is not clear whether the undertaking of caregiving itself is the cause when it is not related to stress (Dich, Lange, Head, & Rod, 2015). Informal carers often have significant demands placed on their time and resources, particularly financially, emotionally and physically (Bodnar & Kiecolt-Glaser, 1994). Carers describe feeling socially isolated and a sense of loneliness, boredom and frustration, alongside feelings such as guilt, anxiety and low mood (Ell, 1996; Kuuppelomäki et al., 2004). Indeed, high levels of depression and anxiety have been associated with caregiving (Bodnar & Kiecolt-Glaser, 1994). Madan and Pakenham (2015) found that carers of individuals with Multiple Sclerosis (MS) had four times more stress-related symptoms and reported lower life satisfaction compared to non-carers.

Despite this however, research has also demonstrated that adult and elderly carers recognise positive effects on their psychosocial well-being as a result of their responsibilities. This is particularly reflected in relationships with the cared for individual and other relatives within the family unit. Carers in a Finnish study described feeling closer to the individual they were caring for and that relations with kin were strengthened (Kuuppelomäki et al., 2004). Carers also reported satisfaction from helping another person and having the opportunity to display love and affection as well as a sense of being wanted, needed and appreciated. Carers have described the caring process as one of personal growth and development which enabled a reassessment and change of their priorities (Pakenham, 2005a).

2.6.2 Physiological

The physical health of carers is also a concern with many individuals associating their caregiving with poorer health (Ferguson & Devine, 2011). A large body of literature exists surrounding the physiological outcomes associated with caring in adults. Research typically utilises symptom inventories and self-reported health to determine the status of a carer's health, but some also take a biological approach and measure aspects of health such as immunity in response to stress and the responsibilities of caregiving.

A founding study in the area of informal carers and their immune response was carried out by Kiecolt-Glaser et al (1987). Using blood samples and immunological assays they found that carers of individuals with Alzheimer's disease (AD) demonstrated poorer cellular immune system control of a latent herpes virus compared to non-carer controls. Further research found that carers had poorer immune function but also reported more respiratory tract infections compared to a non-carer control group (Kiecolt-Glaser, Speicher, Glaser, Dura & Trask, 1991). In 1996 this work surrounding the immunological status of carers was developed by observing immune responses to an influenza vaccine (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan). They found that fewer carers effectively responded to the vaccine than controls and

there was a further distinction between age groups, with seven of 13 carers under 70 years effectively responding compared to nine of 12 controls, and five of 19 carers over 70 years effectively responding compared to 12 of 20 controls. Overall, showing that carers demonstrated a significant impairment in their cellular and humoral vaccine response. Vedhara et al (1999) support these findings from Kiecolt-Glaser and colleagues and found that spousal carers showed poor immune function in response to virus and vaccine challenges compared to a non-carer control group.

Many other studies have utilised the measurement of biomarkers such as cortisol and blood pressure to investigate the physiological impact of caregiving. Raised cortisol levels as a result of chronic stress have been implicated in reduced immunity (Pruessner, Hellhammer, & Kirschbaum, 1999) and therefore demonstrate a mechanism by which the immune systems of those experiencing chronic stress may become compromised. Repeated activation of the stress responses can cause immune function to deteriorate and thus lead to increased risk of health conditions and contracting infectious diseases (Vedhara et al., 2002). In carers specifically it has been found that salivary cortisol levels are significantly higher than controls (Davis & Cowen, 2001). Compared to non-carers, carers demonstrated higher levels of both blood pressure and cortisol (Kim & Knight, 2008). By considering both psychosocial and biological factors (such as cortisol) it is possible to determine associations that may lead to changes in immune or endocrine functioning. Higher caregiver burden has been associated with poorer health status, with individuals reporting the highest number of hours of caregiving demonstrating the highest levels of physiological dysregulation (Dich et al, 2015). The concept of allostatic load has been utilised in longitudinal research and has found that high levels of caregiver burden at the first assessment (equating to more than four hours per week of care) were predictive of higher levels of allostatic load at follow up (Dich et al., 2015). Allostatic load has also been investigated in a population of 87 AD carers, measuring systolic blood pressure, diastolic blood pressure, body mass index, cholesterol, norepinephrine and epinephrine (Roepke et al., 2011). It was found that compared to controls (43 non-carers), carers had significantly higher allostatic load and researchers concluded that allostatic load theory provides a potential explanation for how stress can impact physiological health.

Overall, it is evident that chronic stress, in the form of caregiving, is associated with changes in endocrine and immunological functioning in adult and older carers.

2.6.3 The impact of immunosenescence

A great deal of the literature that has identified the negative impact of informal caregiving has been criticised on the basis that it predominantly investigated elderly carers, a distinct population who experience immunosenescence, that is, a natural waning of the immune system (Vedhara et al., 2002). Therefore, it is argued that rather than chronic stressors, such as caregiving, causing impaired immune functioning, they can act as accelerators of normal age-

related immune dysregulation (Sapolsky et al., 1986). Compared to non-carer controls, carers demonstrated a limited immune response to an influenza vaccine (Kiecolt-Glaser et al., 1996). However further findings shed light upon age related differences, with those who were older showing less response to the vaccine. In particular, of carers aged 70 years or over, only 23.3% mounted an adequate immune response compared to 60% of controls. In carers under the age of 70 years, 53.8% responded effectively compared to 75% of controls. Thus indicating that older carers may demonstrate poorer immune function than younger carers. Researchers concluded that stress related immune dysregulation is likely to have the greatest impact on individuals who already have immune impairment. Vedhara et al (2002) conducted research with non-elderly carers of MS with a mean age of 43 years. Carers reported higher levels of self-reported stress compared to controls, however there were no significant differences between self-reported levels of anxiety and depression. Furthermore, endocrine activity (measured via salivary cortisol and dehydroepiandrosterone (DHEA)) and immunity (measured via response to influenza vaccine) outcomes did not differ between the two groups. Therefore, researchers concluded that compared to elderly carers, those who adopt the role at a younger age may demonstrate physiological resilience and adaptation and be more able to endure the pressure and responsibility of caregiving. This is further supported by research where S-IgA (Secretory Immunoglobulin A; a marker of immune function) secretion was found to be lower in carers compared to age matched controls (Gallagher et al., 2008). However, this difference was only noted in the group defined as elderly (mean age = 63 years), rather than middle aged (mean age = 44 years) or young (mean age = 24 years). Additionally, compared to 22 parents of typically developing children (mean age 44.9 years), 56 parental carers of children with autism or ADHD (mean age 40.3 years) reported greater distress and higher concentrations of inflammatory biomarkers than controls, but did not show different patterns of diurnal cortisol secretion (Lovell, Moss & Wetherell 2012b). This further demonstrates the mixed evidence surrounding adult and young adult carers compared to the relatively conclusive evidence in elderly carers.

Kiecolt-Glaser et al (2003) suggested a pathway through which chronic stressors may have more negative consequences in elderly carers. Their longitudinal study assessed immune functioning in 119 dementia carers and 106 non-carers with a mean age of 70 years at the first assessment period. Levels of the immune marker Interleukin-6 (IL-6) were measured yearly over a period of six years. Increased levels of IL-6 have been linked to a number of age-related health concerns such as cardiovascular disease, osteoporosis, arthritis, type 2 diabetes, certain cancers, frailty and general functional decline. In this study, the rate at which IL-6 increased in carers was four times greater than non-carers and there were no group differences in other factors such as chronic conditions, medication use or health-related behaviours. These findings indicate a pathway through which chronic stressors, such as caregiving, prematurely age the immune system and thus lead to heightened risk of developing age-related conditions such as those described above.

Overall, aging is accompanied by declines in endocrine, immune and cognitive functioning, which all have an impact upon physiological responses to challenging situations. Therefore, stress, especially of a chronic nature, can simulate and in some instances accelerate the process of ageing (Graham, Christian, & Kiecolt-Glaser, 2006). Research with non-elderly and young adult carers suggests that these individuals may not demonstrate the same physiological implications observed in elderly carers which may be explained by less accumulated life stress and therefore less allostatic load. Should this be applied to a population defined as young carers (<18 years), with an immune system relatively unaffected by changes related to age, it may be possible to identify a physiological resilience and the underlying factors supporting this, in order to then apply them in the development of support or interventions.

2.7 Impacts on young carers

Having identified that young carers are a large and significant proportion of informal carers, particularly in England and Wales, research has begun to investigate the impact of being a carer during childhood and adolescence. However, they remain a significantly neglected population and whilst the consequences of caregiving have been established in adult and older carers, this is not true of young carers (Aldridge & Becker, 1993).

Research has demonstrated that when a young person adopts the role of carer there are a number of areas that can be detrimentally effected, these include social, emotional and educational experiences, as well as physical health (Aldridge & Becker, 1999). Some research has suggested that as a young carer's age increases, so do the negative impacts of caregiving. A systematic review identified that in children aged seven to 11 years there were no differences in health and well-being status between carers and non-carers (Bognosian, Moss-Morris & Hadwin, 2010). In adolescents aged 11 to 18 years however, the literature demonstrated a significant negative impact of caregiving. In particular, young carers reported more anxiety and fear, a greater level of separation anxiety, greater levels of depression and higher hostility than non-carers. In a retrospective study, 70% of former young carers stated they felt they had suffered long term psychological effects, with 28% expressing that they had physical health problems directly related to their caring experiences (Lloyd, 2013).

2.7.1 Psychosocial outcomes

The informal carer literature reports a wide range of negative psychosocial impacts from caregiving as a young person. Early research into this area found that the social impact of being a carer can be significantly challenging, particularly due to the stigmatising effects of parental illness (Aldridge & Becker, 1993a, 1993b, 1999). Carers reported that they often experienced pitying comments from peers, teachers, strangers or neighbours that they did not feel comfortable receiving. Due to the level and intensity of some young carer's responsibilities

it was found that there were many restrictions placed upon the social lives of these young people, and that they often lacked opportunities to socialise with peers (Aldridge & Becker, 1993c). As a result this led to social exclusion and isolation from peers, which has been reported in other studies, where young carers felt their social lives were restricted (Thomas et al., 2003). Along with isolation, young carers frequently felt they were different to their peers (Rose & Cohen, 2010) and are often made to feel different because of bullying and name calling from peers (Earley, Cushway & Cassidy, 2007), particularly as a result of their role as a carer (Lloyd, 2013) or their relatives condition (Rose & Cohen, 2010). This may explain why social situations are sometimes avoided by some carers, in a bid to avoid bullying or name calling, however this only further emphasises feelings of isolation and exclusion (Day, 2015).

For some individuals, particularly adolescents, their role as a carer influenced the extent of their friendships and social outings with many describing occasions where they had forgone the opportunity to socialise because their care responsibilities took precedence (Hamilton & Adamson, 2013). Indeed, carers have highlighted the challenge in balancing different areas of their lives, including caring, socialising and education (Rose & Cohen, 2010).

With regard to education, youth caring has been found to have a detrimental effect, with negative impacts on attendance rates and performances, and less opportunity to attend out-of-school activities such as clubs or holiday programmes (Dearden & Becker, 1998). Many young carers find school to be a negative experience and do not succeed as well as non-carer peers (Lloyd, 2013). Svanberg et al's (2010) research provides some explanation for the negative findings surrounding education, with carers describing absences from school, difficulty concentrating and general fatigue as a result of their role.

It is evident from the literature that caregiving at an early age can also have a profound impact upon mental health and well-being. An early study found that former young carers reported feelings of resentment, anger and emotional exhaustion as young people (Frank, 1995). Young carers also report feelings of insecurity, distrust and worry in relation to their caregiving (Sahoo & Suar, 2010). Mental health problems such as stress and depression have been associated with caregiving at a young age (Hamilton & Adamson, 2013; Rose & Cohen, 2010; Thomas et al., 2003) and symptoms such as anxiety, insomnia, low mood and lack of appetite are not uncommon (Ali, Ahlström, Krevers, & Skärsäter, 2012). Anxiety surrounding the cared for individual's condition and health is particularly prominent, and an inability to disconnect from caregiving responsibilities drives feelings of worry and anxiety. Research with 61 young carers found that 60% reported insomnia, 34% had deliberately harmed themselves and 36% had thought about ending their life (Lloyd, 2013). Many of these negative consequences are due to a significant lack of understanding regarding the responsibilities and pressure involved in providing care to a family member (Earley et al, 2007).

Despite the evidence for the detrimental impact of youth caregiving, there have also been studies which have identified positive psychosocial effects. Having a parent with a

physical illness is not always a difficult experience for young people (Bogosian et al., 2010). Some young carers reported a sense of gratification and satisfaction as a result of their responsibilities (Becker, 1995) and a sense of pride and confidence can stem from their identity as a young carer (Rose & Cohen, 2010). Day (2015) suggests that these positive feelings can arise due to the young person seeing the constructive impact of their support upon the person they are caring for. In particular, being a carer can contribute to a felt sense of security and control, in what is often identified as a powerless situation and these feelings can help to counterbalance negative emotions such as shame, isolation, uncertainty and guilt (Rose & Cohen, 2010).

Studies have identified that providing care during childhood or adolescence can lead to an earlier and increased development of maturity and responsibility (Ireland & Pakenham, 2010; Lloyd, 2013; Rose & Cohen, 2010; Thomas et al., 2003). Additionally, being a carer can lead to the acquisition of important life skills required in adulthood (Thomas et al., 2003) that carers stated helped them feel more equipped to live away from home (Rose & Cohen, 2010). These skills included tolerance, independence, helpfulness, nurturance, endurance and sympathy and in many cases research has found that compared to their non-carer peers, young carers demonstrate higher levels of these skills (Sahoo & Suar, 2010). Although many studies highlight the negative impact of caregiving upon social relationships and development in young people, young carers can develop strong social capabilities as a result of the need to interrelate in a way that is focussed and logical when caring for a family member with an illness (Sahoo & Suar, 2010). The act of caring also leads to a better understanding of ill health and disabilities which is beneficial in adult life (Ireland & Pakenham, 2010). Many young people describe the positive impact that caregiving can have on familial relationships, especially with the individual they are caring for, with young carers reporting close loving relationships with parents and feeling closer to family members as a result of caregiving (Ireland & Pakenham, 2010); Lloyd, 2013; Rose & Cohen, 2010 and Thomas et al, 2003). Compared to children of healthy parents, young people of parents with MS did not demonstrate any significant differences in problems associated with health, symptomology, pro-social behaviour, behavioural concerns, attachment or family functioning (Pakenham & Cox, 2012). It was therefore concluded that the role of a young carer does not necessarily guarantee negative consequences, and that with the appropriate level of resources and support, young people can manage their situation and in some cases report benefits.

2.7.2 Physiological outcomes

Compared to the literature surrounding adult and elderly carers, very little research has investigated the physiological impact of caregiving on children and adolescents. Of the research that has been conducted, most studies are qualitative and in many instances retrospective. Frank et al's (1995) study 'On Small Shoulders' asked adult former young carers to reflect on their

experiences. Twenty-eight percent of participants felt their physical health had suffered as a result of their caregiving experiences. Hair loss, back ache, weight loss and psychological asthma were reported as conditions experienced. Additionally, stress related conditions such as epilepsy, allergies and ulcers were exacerbated, indicating that the responsibility and stress of caregiving may have an adverse effect on the physical health of young people. Furthermore, children providing care for a family member were less likely to report their general health as excellent, compared to those without caregiving responsibilities (Lloyd, 2013) and young carers have significantly more physical problems than non-carers, including difficulties sleeping, feeling tired, having a headache and experiencing back pain (Nagl-Cupal et al., 2014), with back strain and back problems in adulthood a common consequence of young caregiving (Thomas et al, 2003).

Although a biopsychosocial approach has not yet been applied specifically to young carers, some research has been carried out with children of parents with an illness. Despite not explicitly identifying children as young carers, these studies can inform knowledge about adjustment in children and provide a starting point for investigating a young carer population. In particular, Turner-Cobb et al's (1998) study investigated adjustment in patients with rheumatoid arthritis (RA) and their children. The six month study found that children who had a parent with RA reported 50% more hassles per week and a smaller social network than children of a healthy parent. Despite this, although cortisol levels were higher in individuals reporting higher stress, there was no difference between children of healthy parents and those with RA. This suggests that although children with parents of RA report poorer adjustment in psychological domains, this is not reflected in neuroendocrine outcomes and this may demonstrate a physiological resiliency or adaptation to chronic stress in these young people. Cortisol patterns in adolescents from families with single and chronically ill parents have also been investigated, as these populations have been shown to report increased stress, however their cortisol levels had not been assessed alongside a control group of children with healthy parents (Sieh et al, 2012). It was found that diurnal salivary cortisol levels did not vary between the groups, and therefore the level of psychological stress was not indicated in the endocrine measures. Researchers concluded that these findings contributed to the argument that children of single and chronically ill parents may show resilience, despite self-reported stress suggesting otherwise.

2.8 Psychosocial factors impacting carer outcomes

It is imperative to identify both protective and risk factors as these can have a significant impact upon the development of interventions which aim to support young people (Slatcher et al, 2015). Psychosocial factors have been identified within the general informal carer literature as having an impact on carer outcomes or contributing to resilience in this population.

2.8.1. Coping

Coping has been defined as a process whereby thoughts and behaviours are utilised in order to manage circumstances that are deemed to be stressful or challenging (Slatcher et al., 2015). Although coping strategies can develop as an individual ages, coping is considered to be a moderately stable personality trait that can counterbalance the damaging impact of harm, threat or stress (Kartalova-O'Doherty & Doherty, 2008), this is particularly true in carers whose experiences can have a negative effect on their physical and psychosocial health (Gignac & Gottlieb, 1996).

Some research has been conducted to investigate coping and the consequences of informal caring in adults. In 54 adult carers of a family member with dementia, the use of rational thinking and problem solving coping was linked to better outcomes on measures of depression, life satisfaction and self-reported health (Haley et al, 1987). Specifically, the pursuit of information relevant to the condition and the carer role was associated with better health outcomes as was greater levels of social support. Emotional discharge however, such as having a 'good cry' or 'venting emotion', was linked to greater reports of depression and depressive symptoms. This was supported in a further study exploring coping style and psychological health in carers (mean age 43 years) of individuals with closed head injury which found that greater use of emotion focussed coping was associated with greater emotional distress (Sander, High, Hannay, & Sherer, 1997).

A quantitative longitudinal study investigated coping in 146 mothers caring for an adult child with an intellectual disability and 74 mothers caring for an adult child with a mental health condition (mean age 66 years for both groups). It was found that higher initial, and increased use of problem-focussed coping predicted lower levels of burden and depressive symptoms whilst the opposite was true of emotion-focussed strategies which not only contributed to increased burden and depressive symptoms but also poorer quality relationships between the parent and child (Kim, Greenberg, Seltzer, & Krauss, 2003).

A more recent study with 125 carers (mean age 74 years) of individuals with AD found that carers utilising fewer positive strategies such as problem solving and seeking social support, and greater negative strategies such as self-blame, denial and avoidance reported increased depressive symptoms, negative affect, fear, hostility and sadness compared to non-carers (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013).

Pakenham and Bursnall (2006) researched 48 young people aged 10-15 years who had a parent with MS and 145 young people of the same age range with healthy parents. The participants of this study were not explicitly defined as young carers. Greater use of approach coping such as problem solving, seeking social support and acceptance, and less use of avoidant coping strategies such as denial, avoidance and wishful thinking were associated with better adjustment. Compared to the control group, those with a parent with MS were found to be less reliant on problem solving and seeking social support.

Qualitative studies have explored populations explicitly defined as young carers and the ways that they cope with the responsibilities of their role. Coping strategies vary widely and helping others is a way in which carers could feel in control of their situation and surroundings (Earley et al, 2007). Additionally, maintaining a close proximity to the cared for individual was deemed helpful, whereby carers could monitor their condition and be close by should they be needed. A qualitative exploration in young adult carers aged 16 to 25 years caring for a parent with mental illness found that young carers often coped by trying to maintain a sense of control (Ali et al, 2012). They also focussed strongly on self-protection and keeping their role as a carer secret due to a lack of understanding from others. Identifying adult role models and sharing worries with other people were also helpful strategies for these young carers.

Very little attention has been paid to psychophysiological factors of burden and coping strategies (Teixeria, Applebaum, Bhatia & Brandao, 2018), however some studies have sought to determine the relationships between specific coping styles and physiological outcomes in carers. A six month longitudinal study with close relatives of individuals with severe acquired brain injury (mean age 49.4 years) found that after 3 months, acceptance and positive reframing were positively associated with cortisol decline, whilst after 6 months, acceptance and religion were positively associated with cortisol change across the day and overall cortisol output (Turner-Cobb et al., 2010).

Many studies have used self-report measures of physical health to determine the impact of informal caregiving on physical outcomes. Carers of early and advanced chronic obstructive pulmonary disease (COPD) were investigated, with 109 and 49 people in each group respectively and an overall mean age of 59 years (Figueiredo et al, 2014). The study found that problem-solving coping strategies were positively associated with better self-reported physical health.

One study has explored the impact of coping style on physiological outcomes in children living with parental illness, but not specifically those defined as young carers. The diurnal cortisol patterns of 645 children (aged 8-15 years) affected by parental HIV/AIDS were explored and mixed results were found (Slatcher et al, 2015). Positive coping was related to higher cortisol levels at wake up, whereas negative coping was related to lower cortisol at wake up. Typically, higher cortisol levels are associated with adverse consequences with regard to health, and therefore lower cortisol levels demonstrate a typically healthy system. However, the researchers concluded that lower morning cortisol levels were due to the down regulation of the stress response due to early adversity. Negative coping was associated with a flatter diurnal cortisol slope in young people living with parental HIV/AIDS which is indicative of negative health outcomes. Overall it was concluded that the use of positive and adaptive coping strategies supported adjustment to parental illness and had a positive impact upon health.

To conclude, there is clear evidence that coping style can impact both psychological and physiological outcomes in populations of carers, with research focusing primarily on adult

and elderly carers and a lack of investigation into the outcomes of coping in young carer populations. Overall, research demonstrates that typically, problem-focussed strategies are associated with more positive outcomes and better adjustment, whilst emotion-focussed strategies are associated with negative outcomes and poorer adjustment, demonstrating that coping style can play a key role in informal carer health and outcomes.

2.8.2 Social Support

Social support has been defined as obtaining emotional concern, tangible assistance, information or consideration through a social network (House, Landis, & Umberson, 1988). The area of social support within carer populations has received a great deal of attention and has been identified as a significant factor influencing carer outcomes.

Early work exploring social support in adult and elderly dementia carers (mean age = 56 years, range 20-87 years) found that social network size, level of social activity and the degree of satisfaction with a social network were related to carer adjustment, particularly in areas of life satisfaction and health (Haley et al., 1987). Since this initial study, further research has built a large body of evidence for the positive impact of social support on carer outcomes. Six different types of social support were investigated (intimate interaction, material aid, advice, supportive feedback, physical assistance and social participation) in a population of 217 carers of frail elders with a mean age 74 years (Thompson et al, 1993). It was found that the different forms of social support did not have equal impact on carer outcomes and that engaging in social interaction for fun and recreation was the most important factor in diminishing the burden of caring. Furthermore, tangible support, intimate interaction and supportive feedback had no impact on carer burden. Research in the area of traumatic brain injury and social support with 60 pairs of carers and their family member who had sustained a traumatic brain injury, found that social support was a powerful moderator of carer psychological distress and that without adequate social support carer distress increased with longer time after injury, cognitive dysfunction and unawareness of deficit in the care recipients. However this effect was not observed in those receiving adequate levels of social support (Ergh, Rapport, Coleman, & Hanks, 2002). Further exploration of social support in relation to the specific outcome of resilience has found that in a sample of 229 individuals providing care for a family member with AD, social support positively influenced resilience, and those reporting the highest levels of family support were more likely to have elevated resilience, with the study concluding that social support is a moderating factor of perceived stress and resilience (Wilks & Croom, 2008). Finally, a 2015 systematic review provides more evidence for the link between social support and resilience, whereby the review of studies involving dementia carers found a positive association between higher levels of resilience and social factors including good social support, satisfaction with social support and individual, family and community resources (Dias et al.,

2015). Overall, there is strong evidence that social support can contribute to positive psychosocial outcomes in adult and elderly carers.

Young carers and young people living with parental illness have also been studied with regard to their social support networks and their impact on psychosocial outcomes. Young people living with a parent who had Huntington's Disease demonstrated that those with strong support from others were able to cope more successfully than those with weaker social support networks (Forrest Keenan, Miedzybrodzka, Van Teijlingen, McKee, & Simpson, 2007). In 100 young carers aged 10-25 years, it was found that social support was the strongest predictor of adjustment, with coping and choice acting as weaker predictors, and stress appraisal proving to be unrelated to adjustment (Pakenham, Chiu, Bursnall & Cannon, 2007). A mixed methods study (Ali, Ahlström, Krevers, Sjöström, & Skärsäter, 2013) found that in carers under 25 years old, whilst factors such as appraisal, coping, coping resources, social support and caregiver context all predicted adjustment, social support was the strongest predictor. The quantitative findings of this study identified that most often, the social support network of a young carer typically includes friends, siblings and parents, highlighting that there are various sources of social support utilised by this population. Although social support in relation to psychosocial outcomes has been studied in young carers, the impact of this factor of physiological adjustment is yet to be explored. Research has however identified links between social support and physiological outcomes in adult and elderly carers.

An early study by Kiecolt-Glaser et al (1987) used psychosocial measures and blood samples from 34 carers of those with AD and found that carers reporting attendance at a support group considered themselves significantly less lonely than those who did not attend, and also had higher percentages of Natural Killer (NK) cells than non-support group members, indicating a greater immunological response. This research was extended to 23 spousal carers of cancer patients with a mean age of 48 years (Baron et al, 1990). Those reporting high levels of social support showed healthier immune functioning than those reporting lower social support. Researchers concluded that even under extremely stressful circumstances social support can be highly beneficial. Kiecolt-Glaser et al (1991) conducted further research in the form of a longitudinal study with 69 carers of individuals with dementia and 69 matched controls. The initial sample was followed up 13 months later and during this time the cellular immunity of carers had significantly declined compared to controls. However, those reporting low levels of social support at the first assessment and showed the most distress regarding dementia-related behaviour problems demonstrated the largest negative changes in immune function at the 13-month follow-up.

The biomarker cortisol has also been utilised to explore the relationship between social support and the physiological impact of caregiving in a sample of 87 carers with a mean age of 63 years (Kim & Knight, 2008). Of particular interest in this study was the consideration of quality and quantity of social support. If was found that carers reporting poorer quality of

instrumental social support showed raised cortisol levels, a factor that suggests greater physiological stress. This was also reflected in a more recent study (Faw, 2016) with 40 parental carers of children with severe disabilities (mean age 48.65 years, range 25-77) which demonstrated that after receiving a short supportive interaction with a member of their social network, carers showed decreases in their cortisol levels. Faw (2016) noted that quality of support played a key role in this interaction with those receiving the highest quality interaction showing the most pronounced reductions in cortisol levels compared to baseline levels.

Some studies have sought to explore the impacts of social support on health more generally, utilising self-report measures of health rather than physiological biomarkers. A meta-analysis of informal carer literature related to physical health determined that lower levels of informal support were related to worse physical health symptoms (Pinquart & Sorensen, 2007). These researchers also offered possible explanations for the mechanisms through which social support can promote adaptation and positive adjustment in carers. These suggestions included social support networks having the potential to decrease carer stressors, assist in the development of helpful coping strategies and encourage positive health behaviours. Finally, a recent study of 637 dementia carers found that received support, social network size and negative interactions were significantly associated with self-rated health. In particular, carer burden was found to be a mediator of associations between social network and self-rated health, and negative interactions and self-rated health (Xian & Xu, 2019).

Overall, the identification of social support as a significant and helpful factor in the management of outcomes in carers is particularly valuable, as these findings can allow the development of services and interventions to be well informed and evidenced-based (Branscum, 2010).

2.8.3 Benefit finding

As previously established, though carers report negative impacts of their experiences they also identify positive consequences. This has been called 'benefit finding' which has been further defined as a form of cognitive adaptation whereby individuals evaluate challenging situations positively and as a result minimise or divert the potentially negative implications of such a situation (Taylor, 1983). Benefit finding has been conceptualised as both a process used to cope with a challenging event, but also as an outcome of an event (Affleck & Tennen, 1996; del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011). Research exploring benefit finding in informal carer populations has predominantly found evidence that benefit finding promotes positive adaptation (Cheshire, Barlow, & Powell, 2010; Kayfitz, Gragg, & Orr, 2010).

An early mixed methods study of benefit finding explored the impact of multiple sclerosis on carers and those receiving care (Pakenham, 2005a). Two-hundred and sixty-seven dyads completed initial questionnaires with 155 completing follow up questionnaires three

months later. Seven categories of benefit finding were identified including interpersonal, insight into illness/hardship, personal growth, life priorities/goals, appreciation of life, caregiving specific and health. Statistical analysis identified that benefit finding was positively related to carer adjustment and concluded that there were two factors of benefit finding; personal growth and family relations growth. A further mixed methods dyad study with 64 carers and 46 care recipients explored benefit finding in the context of HIV/AIDS and in relation to carer adjustment, stress and coping (McCausland & Pakenham, 2003). Content analysis of interview data identified eight benefit categories including personal growth, increase in understanding of others, positive personality change, increased knowledge of HIV/AIDS, the start of a new relationship, strengthening of an existing relationship with care recipient, sense of satisfaction and achievement and gained perspective. Statistical analysis revealed that poorer adjustment was significantly inversely correlated with social support and benefit finding. Benefit finding was also significantly associated with seeking social support, using social support and problem-solving coping. These studies concluded that benefit finding is a concept that warrants further investigation with regard to adaptation in carers, particularly those providing care for individuals with MS or HIV/AID's (McCausland & Pakenham, 2003; Pakenham, 2005a).

Further studies have focussed on benefit finding within the context of cancer caregiving and have identified in adult (mean age = 54 years) family carers that six domains of benefit finding exist including acceptance, empathy, appreciation, family, positive self-view and reprioritisation (Vitaliano, Schulz, Kiecolt-Glaser, & Grant, 1997). Furthermore, benefit finding has been found to be associated with life satisfaction and depression as a global concept but differences within the different domains of benefit finding were also noted, with acceptance and appreciation of relationships being associated with better adjustment and becoming more empathetic and reprioritising values being associated with greater symptoms of depression (Kim, Schulz, & Carver, 2007). A further study explored benefit finding in relation to carer burden, perceived stress, optimism, resilience, self-efficacy, perceived support and psychological distress in 842 female carers ranging from 19 to 74 years of age (Cassidy, 2013). The study found that global benefit finding and its individual dimensions were significantly negatively correlated with psychological distress, perceived stress, burden of care and perceived burden of care. Furthermore, significant positive correlations were identified between resilience, optimism, self-efficacy, social support and benefit finding, with 37% of the variance in benefit finding explained by resilience, optimism, self-efficacy, family support, friend support, burden of care and perceived burden when controlling for age and education. A mixed methods approach was used to explore benefit finding in 40 maternal carers of paediatric cancer survivors who had a mean age of 40 years (Willard, Hostetter, Hutchinson, Bonner & Hardy, 2016). The study found that nearly 83% of participants reported some form of benefit from their experience, with a range of 1 to 14 benefits identified by mothers in the areas of social support, personal growth and child-specific. Quantitative analysis identified that there was no significant

association between number of reported benefits and parenting stress or emotional functioning. However, fewer reported benefits were associated with more guilt and worry, unresolved sorrow and anger, long-term uncertainty and fewer emotional resources. The study concluded that benefit finding was associated with better adjustment in maternal carers. The research exploring the cancer caregiving experience provides evidence for benefit finding as a valuable asset in carers over 19 years old, which promotes positive adjustment and may lead to resilience in this population.

Researchers explored associations between benefit finding, quality of life and social support in 84 family carers (age unreported; Brand, Barry, & Gallagher, 2016). Findings showed that benefit finding, optimism and social support were predictive of quality of life, and that the association between benefit finding and quality of life was mediated by social support. Therefore, carers who reported greater benefit finding had greater perceived social support which in turn positively impacted quality of life. Many of the researchers conducting the aforementioned studies determined that benefit finding was an important factor in promoting positive adjustment and quality of life in carers, and argued that their findings provide the basis and rationale for future research exploring the impact of benefit finding interventions within this population (Cassidy, 2013; Kim et al., 2007; McCausland & Pakenham, 2003; Pakenham, 2005a).

Two studies have tested the efficacy of benefit finding interventions in carers. The first explored the impact of a written benefit finding intervention, particularly surrounding psychological functioning in chronically stressed carers (Lovell, Moss, & Wetherell, 2016). Sixteen carers of children with autism and 17 non-carer controls took part in the study, with mean ages of 46 years and 43 years respectively. This particular intervention was of interest due to its relative inexpensiveness and its home based style which was well suited to those unable to leave the home and access other interventions such as professional support or support groups. The study found that carers in the benefit finding intervention condition were less likely to demonstrate anxiety scores that met clinical criteria for mood disorder three months after the intervention. A further study in 2017 conducted a double-blind randomised controlled trial to determine the impact of benefit finding in 96 carers on depression symptoms, burden and psychological well-being (Cheng et al., 2017). Participants were randomly assigned to either the benefit finding, simplified psychoeducation or standard psychoeducation condition, receiving four home-based fortnightly interventions of 3 hours over 2 months. Findings showed that benefit finding participants reported fewer depressive symptoms after treatment than both psychoeducation conditions, and reported less burden after intervention than those in the standard psychoeducation condition. These two intervention studies demonstrate that benefit finding can have both immediate and lasting positive impacts on carer burden and psychological well-being, suggesting that benefit finding is a factor that positively contributes towards

adjustment and adaptation in the face of the chronic stress of caregiving in adults and the elderly. Research surrounding benefit finding in young carers exists, but is more limited.

Researchers developed the Young Carers Perceived Stress Scale (YCPSS; Early, Cushway, & Cassidy, 2006) which identified a dimension titled 'personal value of role' which was further developed by Cassidy and Giles (2013), renamed as 'Benefit finding' and explored in a population of 329 young carers (aged 12 to 16 years) in relation to additional variables such as social recognition of role, school impact, social impact, family impact and caregiver burden. It was found that benefit finding was significantly and positively correlated with social recognition of the role and significantly negatively correlated with social, family and school impact, and perceived burden. The benefit finding scale was used in further research, specifically in relation to resilience in a population of 442 young carers aged 12 to 16 years (Cassidy, Giles, & McLaughlin, 2014). Findings showed that resilience and benefit finding positively correlated with life satisfaction and positive mental health and inversely with stress appraisal and negative mental health. In regression analyses, resilience and benefit finding were predictive of 28% of variance in life satisfaction and family support, social recognition of the role, resilience and benefit finding contributed to a total of 61% of variance in positive mental health.

Overall, there is evidence in carers of all ages that benefit finding can positively impact psychosocial outcomes, however research is yet to explore the relationships between benefit finding and physiological outcomes in relation to stress, adjustment and physiological resilience.

2.8.4 Resilience

The concept of a resilient carer or child is not new, and as early as 1989, Werner asserted that despite growing up in a challenging and stressful environment, including parental illness, children can show remarkable resilience. Positive temperament, strong social support, positive self-concept, assertiveness and independence encourage resilience, particularly in young people (Werner, 1989). Five criteria for resilience have been described and applied to the situation of caregiving (Donnellan, Bennett & Soulsby, 2015). The first is that a substantial challenge must be present (e.g. caregiving), and the second is that distress or stress is not evident. This is followed by the third criteria that a life of meaning and one with satisfaction must be preserved despite the challenge being faced, and fourth the individual must continue to actively participate in their life. Finally, their current life must be perceived as positive by themselves. With respect to carers, resilience can encapsulate the individual differences which may enable some carers to cope well with their situations and roles (Kneebone & Martin, 2003). Resilience can involve psychological adaptation and physiological adaptation, and specific factors have been identified that influence both. Coping mechanisms, perceived control, optimism, social support, early life experiences, education, genetics and sleep can mediate

psychological resilience whilst neuro-endocrine reactivity, genetics, environmental factors, nutrition and sleep can mediate physiological resilience (Kneebone & Martin, 2003).

Knowledge surrounding factors that help carers develop resilience is scarce, though many studies discuss resilience very few measure it as a unique variable and therefore tend to use it as an overarching term to capture a number of factors that relate to adjustment in carers (Donnellan et al, 2015). In a qualitative study of older spousal carers of individuals with dementia, those who were most resilient did not demonstrate only positive thinking or optimism, but also found meaning in their role, for example viewing it as a chance to develop skills around and knowledge of dementia (Donnellan et al, 2015). Non-resilient carers typically reported directing their attention mostly to features of their lives that had been lost due to their role, or parts of their lives that had become lastingly damaged or changed. It is factors such as these that can determine whether a carer perceives their responsibilities as a burden, or considers them to be an enriching aspect of their life.

A quantitative study with 61 family carers of individuals with traumatic brain injury or spinal cord injury (mean age = 52 years) found a positive association between family resilience and positive affect and a negative association between negative affect and caregiver burden (Simpson & Jones, 2013). A further study exploring 110 carers of individual with AD (mean age = 63 years) found a relationship between resilience and caregiver burden, whereby as carer resilience increases, their burden decreases (Scott, 2013). Research with AD carers has continued and a study involving 106 carers of individuals with mild and moderate Alzheimer's disease (mean age = 58 years) found that resilience was negatively correlated with carer depression and anxiety symptoms with those demonstrating higher resilience also reporting higher quality of life. Finally, resilience was negatively correlated with self-reported emotional problems (Rosa et al., 2018).

In terms of psychosocial outcomes in young carers in relation to resilience, a study exploring 442 young carers between the ages of 12 and 16 years (mean age = 13.5 years) in relation to benefit finding and resilience noted additional effects between resilience and other variables measured within the study (Cassidy et al., 2014). In particular, resilience was negatively associated with caregiver burden, stress appraisal and negative mental health, and was positively associated with friendship support, family support, life satisfaction and positive mental health.

Turning to physiological outcomes in relation to carer resilience, Ruiz-Robledillo et al (2014) studied 67 parental carers of children with Autism Spectrum Disorder (ASD) who had a mean age of 67 years. Carers were categorised as high, medium or low resilience and self-reported their general health status. Cortisol awakening response, stressful life events, social support and burden were also assessed. It was found that resilience was negatively correlated with somatic symptoms, anxiety, insomnia and perceived general health for all three groups. Furthermore, resilience was negatively correlated with the cortisol awakening response,

demonstrating that greater resilience was associated with lower cortisol levels. Resilience accounted for 10% of variance in total perceived general health and 33% of variance in cortisol levels. Carers in the low-resilience category demonstrated significantly higher levels of morning cortisol levels than those in the medium and high resilience groups. The study concluded that there is evidence for the impact of resilience on physical health and physiological outcomes, and that carers with low resilience may demonstrate a compromised ability to cope with the stress of caring.

A systematic review of the psychobiology of dementia caregiving in adult and elderly carers (Harmell, Chattillion, Roepke, & Mausbach, 2011) found evidence that resilience has both direct and interactive effects on physical health outcomes in dementia carers. In particular, authors note that resilience can have broad and beneficial effects on biomarkers and clinical markers of disease such as blood pressure. A more recent systematic review of resilience in dementia carers (Dias et al., 2015) identified that higher levels of resilience were associated with less depression and better physical health.

In recent years more consideration has been given to researching children who are able to survive, and in some instances thrive, despite facing substantial hardship and challenging early life experiences (Slatcher et al., 2015). Resilience is frequently researched from a psychological perspective, however some research has explored the physiological impact of this factor. Although little research has been conducted regarding resilience in young carers specifically, Chi et al (2015) investigated perceived stigma, resilience and HPA axis function in 645 children of parents diagnosed with HIV/AIDS. An indirect effect of resilience on diurnal cortisol was identified through lower perceived stigmatisation. The researchers concluded that children who demonstrate greater resilience may have more internal resources which enable them to cope effectively with stressors or challenging situations in their lives and this can have a further impact upon physiological health.

Although research specifically investigating the impact of resilience on psychophysiological outcomes is lacking, the evidence that does exist suggests that resilience as an overarching concept, encompassing a number of factors and resources, can promote positive outcomes and adaptation in carers and children of parents with an illness.

2.9 Summary

In conclusion, this literature review has identified that the need for informal carers has increased in recent decades and in many instances, for a host of reasons, these caregiving responsibilities fall upon children or young people within the family. Identifying young carers is inherently difficult due to their hidden nature and the associated stigma with the role and therefore research surrounding this population is limited. The literature surrounding adult and elderly carers however is considerably vaster and has identified a wide variety of negative and positive psychosocial outcomes and a substantial number of negative physiological impacts of

caregiving. Similar to adult and elderly carers, positive and negative psychosocial outcomes have been found in young carers, however there is a sizeable gap surrounding physiological consequences in this population, with initial studies recruiting children of parents with an illness, rather than identifying them explicitly as carers. A number of individual differences have been identified as potentially impacting the health and wellbeing outcomes of those who adopt a carer role, including coping, social support, appraisal, self-efficacy, early life experiences and resilience, with much of the stress research supporting the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and much of the resilience research supporting the socioeconomic model of resilience (Windle & Bennett, 2011).

Researchers have highlighted the importance of studying carer populations, not only to provide support and assist in effective adaptation to the role (Kartalova-O'Doherty & Doherty, 2008) but also to study a chronically stressed group of individuals whereby stressors can be erratic and gradually worsen. Therefore, carers provide an opportunity for conclusions to be drawn about chronic stress on a wider scale and perhaps applied to other populations (Haley et al., 1987). Furthermore, researchers are calling for a developmental approach to be taken in order to gain knowledge about the influence of stress on immune and endocrine systems, so that physiological changes throughout the lifespan can be understood (Graham et al., 2006). A great deal of the literature surrounding this area recruits elderly carers, who are not representative of the informal carer population as a whole (Vedhara et al, 2002), and compared to the research conducted with adult and elderly carers, explorations of young carers are lacking and few studies have focussed upon child and youth caregiving experiences (Earley & Cushway., 2002; Soothill et al., 2003). Those that do investigate this group of individuals typically use retrospective designs or provide findings that are predominantly descriptive or subjective in nature (Pakenham et al., 2006). Furthermore, studies which have researched illness or disability within a family context tend to place emphasis on the adverse and harmful impacts of caregiving, but it has been clearly identified that although these consequences do exist, positive outcomes are also present (Aldridge & Becker, 1999). Therefore, adopting a resilience approach to researching this population as opposed to a vulnerability approach could allow factors which support adaptation and resilience to be identified and thus applied to appropriately support children and young people, and improve their capacity to cope effectively (Svanberg et al., 2010).

Finally, it is evident that as physiology changes with age, so do the effects of stress, and due to the older age of many carer participants these findings may not represent the carer population as a whole. By investigating individuals under chronic stress due to their caregiving role and responsibilities, who do not have the age associated dysregulation of the HPA axis and immune system witnessed in older carers, it may be possible to identify factors that enhance coping and resilience and further determine the pathways through which stress can impact physiological health (Lovell & Wetherell, 2011). Indeed, the psychophysiological basis of

resilience is under investigated and provides an important opportunity for research (Dhabhar, 2013), as evidence by the literature presented in the current chapter.

Chapter three: Methodology

3.1 Chapter overview

This chapter begins with a brief history of research with young carers, contextualising the current research. It then provides an overview of epistemologies, research designs and analytical approaches relevant to the current research and discusses methods for assessing stress and psychosocial factors. Rationale for the methodological and perspective decisions made in the current programme of research are provided throughout. Justification of a mixed methods approach is given and the typology and analytic strategy are presented. The chapter ends with discussion of the challenges surrounding research with children and young carers including ethical considerations.

3.2 History of young carer research

It is more than 25 years since the initial dialogue surrounding young carers began, with research and debate taking place in the late 1980's and early 1990's (Aldridge, 2018). It was at this time that researchers began to call the population they were studying 'young carers', however research has explored this group of young people since the late 1950's (Arnaud, 1959), with clinicians attempting to identify early signs of maternal deprivation in children of parents with an illness or disability (Rutter & Madge, 1976). This early research did not tend to use the term young carer, and instead focussed on the impact of having a parent or sibling with an illness or condition. Whilst many of these studies do not explicitly state that these young people were providing care, this was often assumed to be the case (Banks et al, 2001).

In 1996, Olsen cited studies from the 1990's which had taken the first steps to identifying the numbers of young carers that existed in the UK at that time, and suggested up to 10,000 young people were a primary carer (Fallon, 1990; O'Neil & Platt, 1992; Olsen, 1996; Siddal, 1994). However, a call was made for further research to clarify the proportion of young people providing informal care and it was argued by Olsen (pg43) that "virtually nothing is known about the gender, ethnic and age composition of this group, particularly regarding intensity and nature of caring involvement". Perhaps due to this call and the growing awareness of young carers, in the 1990's a number of high profile studies were conducted to investigate this population. The level of knowledge surrounding young carers has changed quite considerably, with research which addresses the dynamics and characteristics of young carers and begins to paint a fuller picture of who young carers are and what they do.

Though research into this area was required and welcomed, due to its exploratory nature it did not come without criticism regarding sample sizes, assumptions and theoretical foundations. Historically, research with young carers overwhelmingly focussed on the negative impacts of having a disabled family member (Banks et al, 2001). This critique is supportive of previous assertions that the experience of being a young carer are "almost wholly" presented in

negative terms in research conducted up until the mid 1990's (Olsen, 1996, pg44). This approach and the identification of negative outcomes, has enabled support services to be developed specifically for young carers, allowing them to access support to negate the impact of youth caregiving. However, these approaches tend to focus on managing the negative impacts once they have begun to take place, rather than taking a proactive or preventative approach. More recently, young carer research and carer research in general has begun to focus on the possible benefits of being a carer, in contrast to the perceived compensation, whereby being a carer can result in a trade-off of care or activities being provided (Olsen, 1996).

In 2017, Aldridge assessed the current status of young carer research, policy and practice and highlighted more recent work that had attempted to determine the number of young carers in the UK. Data from the 2011 census indicated that there were approximately 166,000 young people under the age of 18 years old providing care to a parent or other relative, in England and Wales. Despite this, numbers of young carers are consistently debated and many statistics tend to contradict each other, for example a study conducted by the BBC (British Broadcasting Corporation) estimated that there are approximately 700,000 young carers in the UK. This study has been criticised on the basis of a flawed methodology and therefore unreliable evidence (Aldridge, 2018), but it contributes to the lack of clarity surrounding the true number of young people providing care.

In 2014, the Department for Education (DoE) commissioned a programme of research which adopted both qualitative and quantitative methods in order to shed some light on the contexts in which young people provide care and the impacts of doing so. This research focussed specifically on young carers aged 5 to 17 years in England and is the most recent, wide scale, investigation of its type. Findings from this research demonstrated the definite negative impact of caregiving as a young person, but also highlighted a number of positive outcomes which young carers identified within their caregiving role. This demonstrates a move away from exploring only the negative impact of caregiving. The identification of benefits, or positive factors, which can allay the negative impact of caregiving are now becoming a focus of research, specifically in terms of coping and resilience.

3.3 Epistemology

An epistemology is a theory surrounding knowledge and truth which through its unique perspective explains how knowledge is acquired and how truth can be defined (Slevitch, 2011; Willig, Rogers, Yardley, & Bishop, 2017). The root of the fundamental differences between quantitative and qualitative approaches lies within their epistemology and is what shapes the nature of these different perspectives (Lincoln & Guba, 1985). The current programme of research has adopted a pragmatic epistemology.

Quantitative approaches are based on an epistemology that stems from positivism and a realist orientation with the assumption of a single reality of truth (Slevitch, 2011). Therefore,

reality is viewed as a phenomenon that can be measured with the use of valid and reliable tools. In quantitative research, questions and hypotheses are developed and tested through the collection of data, which is typically collected using experimental approaches, naturalistic approaches, surveys, questionnaires and biological measures (Guba & Lincoln, 2004). Adequate sample size is considered a vital factor to ensure results lend themselves to generalisability and representativeness. Within a quantitative epistemology, the researcher is seen as unconnected and independent from the researched which allows a researcher to investigate a topic without influencing it or being influenced by it (Sale, Lohfeld, & Brazil, 2002).

In contrast, a qualitative epistemology is based on a constructionist or interpretive viewpoint, whereby there is no single or unique truth, but rather multiple realities exist due to the way an individual or group, constructs or interprets the world around them (Slevitch, 2011). Bishop and Yardley (2015) argue that the root of reality and knowledge lies in the way in which individuals perceive and relate to the world, and state that these perceptions are influenced by assumptions, previous experience and pre-existing concepts. Within a qualitative epistemology, a researcher and their topic cannot be separate entities, as they are interwoven. It is not possible for a researcher to conduct their work free from the influence of socio-cultural assumptions and previous life experience. In this sense, it is not possible to develop value free and objective knowledge as a quantitative epistemology would suggest. Therefore, the aim of qualitative approaches is to develop a deeper understanding of a research area, through the lens of those involved in the research (Bryman & Bell, 1988) and to focus on developing a knowledge of the phenomenon that is rich in meaning, interpretation, process and context (Guba, & Lincoln, 1994). In qualitative research sample size is not a concern but those who participate in research should be involved based on their ability to provide valuable and rich data (Walsh, 2003).

With the aim of exploring the understudied topic of young carers and resilience, both quantitative and qualitative approaches are relevant and offer value to the overall programme of research whilst effectively addressing the research questions investigated. It is for this reason that a third epistemology, pragmatism, was adopted for the purpose of this research. Despite their fundamental and significant differences, qualitative and quantitative research methods are not necessarily incompatible and pragmatism allows for a mixed methods approach. Pragmatism was developed as a response to the realism-constructivism divide (Cornish & Gillespie, 2009) and offers a middle ground between two very different epistemologies, rejecting traditional dualisms (Johnson & Onwuegbuzie, 2004).

Mixed methods research is defined as an approach whereby a researcher chooses to combine or mix both quantitative and qualitative methods, language techniques and analysis, based on the idea that there is no single best method, and that each method has its own unique merits in reaching a particular research goal (Cornish & Gillespie, 2009). This is the case for the current research, whereby quantitative methods (questionnaires and physical hair samples) and qualitative methods (photo elicitation interviews) are used to address the key research questions

proposed, with a systematic review and exploratory qualitative interview study forming the foundation for further quantitative investigation. This is in line with the view of pragmatism that the best research method is the one that solves the research problem at hand.

In contrast to the divisive quantitative and qualitative epistemologies, pragmatism views knowledge and realism as concepts which are constantly renegotiated and open for debate and reinterpretation based on the presentation of new data and the goal of reaching an explanation which enables the best understanding of research findings (Johnson & Onwuegbuzie, 2004). Understanding is viewed as a means to initiate action, and therefore knowledge should be appraised based on whether it serves a purpose in addressing research questions and overall aims of the research (Cornish & Gillespie, 2009). Pragmatism is embedded within action as its aim is to solve problems that arise through the observation of individuals' day-to-day experiences whilst taking a value-oriented approach, thus leading to the endorsement and encouragement of practical theory, which can play a valuable role in health research (Cornish & Gillespie, 2009; Johnson & Onwuegbuzie, 2004). The current research programme has an ultimate aim of informing future interventions and provision for young carers, thus, this action focussed vision tackling issues such as poor psychosocial outcomes in young carers is in line with pragmatism's value of purpose and action.

Pragmatism does not disregard epistemological differences in order to find a middle ground, but rather it acknowledges them without allowing them to become a barrier that cannot be overcome (Bishop, 2015). As pragmatism seeks to evaluate knowledge on the basis of whether it serves its required purpose rather than whether it accurately reflects an underlying reality, it is therefore fruitless to assess the benefits and drawbacks of a specific method without considering the research question being asked and the intended purpose of the knowledge that will be obtained (Cornish & Gillespie, 2009). Bishop and Yardley (2017) argue that the assumptions and aims of both quantitative and qualitative approaches must be acknowledged and considered as part of the process of choosing a suitable research method. In the current research, the underlying assumptions of each methodological approach were considered in their own right, prior to consideration of combining and mixing methods. This ensured the primary researcher (TH) was clear on the contributions that both approaches could make to the overall research programme and meant that decisions were made with epistemological approaches and the research questions in mind.

Essentially, pragmatism is considered a framework that can allow both quantitative and qualitative approaches to be embraced within research and emphasises a common aim for all research to lead to constructive change in the world (Bishop, 2015; Willig et al., 2017). Indeed, Sale et al (2002) highlight that there are some common factors between both quantitative and qualitative researchers, who recognise the shortcomings of knowledge and the importance of linking both theory and empirical work. Furthermore, they stress that all researchers have a responsibility to conduct rigorous research in a conscientious manner, whilst being open to

critical feedback and disseminating their findings. Despite these shared goals and understanding, there are arguments both for and against the use of mixed methods research.

3.4 Rationale for a mixed methods approach in the current programme of research

Mixed method approaches are disentangled from the paradigm debate and see the benefits of mixing both quantitative and qualitative methods (Morgan, 2007). Both approaches are useful and it is beneficial to draw from strengths and minimise weaknesses, or as Johnson and Onwuegbuzie (2004, pg18) suggest, researchers should aim to collect different types of data via different methods in order to collect a data set that leads to "complementary strengths and non-overlapping weaknesses".

Although there are many benefits to taking a mixed methods approach, there are some drawbacks, most of which arise from failing to consider the aspects of both quantitative and qualitative epistemologies as individual approaches before seeking to combine them. Some researchers argue that mixed methods approaches should be avoided because they are simply and wholly incompatible (Howe, 1988) whilst others warn of the philosophical and technical challenges that can arise (Bishop, 2015). Indeed, Johnson and Onwuegbuzie (2004, pg19) pose the questions of "For whom is a pragmatic solution useful?" and "where should the mixing occur?" addressing the important issue of how and when to combine the different methodological approaches to maximise them both. Finally, due to its mixed-method approach, and the narrow focus on solving specific problems, pragmatism runs the risk of only contributing to incremental change, as opposed to a more significant, central or innovative change in the wider society (Johnson & Onwuegbuzie, 2004).

To avoid these pitfalls in the current research programme, the strengths and limitations of each method were considered with the specific research questions in mind, at each stage of the research. Thus, methods were assessed and chosen for their ability to contribute to the overall understanding of the area of young carers when combined, but also with their individual characteristics in mind.

3.4.1 Characteristics of quantitative and qualitative designs

Beyond the specific and individual epistemologies that underlie quantitative and qualitative research approaches, there are also a number of fundamental methodological characteristics which distinguish the two approaches from each other (Willig et al., 2017).

Quantitative studies within the area of stress research typically take the form of experimental or naturalistic designs. Experimental designs are often used in the context of an acute social stress paradigm, whereby experimental versions of naturalistic acute stress (for example, public speaking) are introduced to trigger a stress response and allow the psychological and physiological aspects of stress to be investigated. Naturalistic field designs on the other hand involve the assessment of stressors that occur in the participants natural

environment rather than simulating them within an experimental setting. The nature of the naturalistic approach is practical and efficient for the assessment of chronic stressors such as caregiving (Allen et al., 2017). Naturalistic field designs are useful for the collection of cross-sectional and longitudinal data which is typically collected via questionnaire, interview and biological samples such as saliva, blood or hair to measure a range of endocrine, allostatic or immune biomarkers connected to stress. Examples of naturalistic field designs include the use of the common cold (Cohen, Tyrrell, & Smith, 1993, 2010; Swartz, 1991) and wound healing (Glaser & Kiecolt-Glaser, 2005; Kiecoltglaser, Marucha, Malarkey, Mercado, & Glaser, 1995) as paradigms to explore the impact of chronic stress on health and immunity.

The current research investigates caregiving, widely considered a chronic stressor, specifically in the context of young people providing care. A naturalistic field design adopting interviews, questionnaires and physiological samples (outlined below) is deemed most appropriate as participants are immersed within their experiences of this chronic stressor. When an individual is experiencing a stressor in their day to day life such as caregiving, this can form a paradigm within which to explore the impacts of chronic stress. Though it may be possible to induce stress through the prospect of or imagining of providing care to a family member, this is neither necessary nor ethical when individuals already experience the stressor in their daily life.

Typically, quantitative studies such as those using the designs described above, are conducted when a clear and testable hypothesis has been developed as a result of careful reviews of current literature and theoretical models that exist within the field. Qualitative studies on the other hand tend to be developed on the basis of in-depth understanding that exists surrounding the context of an area to be studied. When considering participant samples, quantitative studies aim to have a sample which is representative of the population being studied in order to allow for generalisability of findings, whilst qualitative research selects a sample based on their ability to contribute to understanding the area of study and to provide rich data from their views and experiences. With regard to bias and validity, quantitative research implements processes to reduce systematic bias in observations, such as through the use of blind data collection or standardised measures, whilst increasing internal validity through the reliability of measures and attempting to control external factors (Bryman, 2006). Qualitative research however does not address systematic bias, but should ensure that the influence of researcher perceptions, experiences, beliefs and views are reflexively considered and managed in a sufficient manner whilst maximising external validity through methods which allow for open responses or allow for real-world data to be collected. Finally, quantitative studies are typically analysed using statistical procedures where the appropriate assumptions of the data are met and significance is determined. Qualitative data on the other hand are typically analysed using an in-depth process which often requires immersion in the data and the careful use of validation procedures such as triangulation (Morgan, 2007).

3.4.2 Characteristics of literature review designs

In addition to empirical designs such as those described above, there are also different methodologies for reviewing areas of literature and one such approach is to conduct a systematic review.

A systematic review follows specific and scientific methods to rigorously review literature in a way that aims to limit bias whilst identifying, appraising and synthesising relevant research of both quantitative and qualitative design (Petticrew & Roberts, 2008). Systematic review methods are typically specified in advance, much like empirical studies, and follow a systematic process to search for, include and exclude research from the review. As such, the systematic review becomes a scientific tool for the assessment of literature, enabling individual studies to be understood in the context of other similar or related research (Chalmers, Enkin, & Keirse, 2006).

A systematic review can enable the assessment of intervention efficacy, methodological examination of studies addressing the same or similar research questions, the exploration of questions surrounding etiology and inform policy making decisions (Petticrew & Roberts, 2008). Of more relevance to the current programme of research, a systematic review can provide a picture of the balance of evidence in relation to a specific topic, can enable the development of recommendations for future research and can clarify areas of uncertainty whilst identifying where little or no research has been done (Petticrew & Roberts, 2006). Ultimately, a systematic review allows researchers to examine and become familiar with the body of literature surrounding a specific area (Sheldon, 1998) by providing a summary and synthesis of large quantities of data and research that might otherwise be unmanageable (Mulrow, 1996). It is argued that systematic reviews are a research method in and of themselves, and are similar to a survey, whereby the literature is surveyed rather than participants (Petticrew & Roberts, 2006).

Petticrew and Roberts (2006, pg21) stipulate that it is important to consider whether a systematic review is needed before a new piece of primary research is conducted and argue that though it is "simply good scientific practice to know how a new study builds on existing evidence" it is an infrequent occurrence within social sciences research. It was deemed important to conduct a systematic review of the general informal carer literature for three key reasons. First, a systematic review assessing the literature surrounding coping and adjustment in general informal carers did not exist and therefore was vital to determine the extent to which factors promoting positive or negative outcomes had been identified thus far. Second, the general literature review determined that research surrounding coping and adjustment in young carers was scarce, and thus a systematic review was required in order to provide evidence of past young carer research that sought to explore factors impacting adjustment in this population. Finally, with a view to conducting primary research with young carers, it was necessary to gain an overview of the literature thus far so that the new research could be situated within the

context of general caregiving and for it to be clear how this new research may build upon existing literature.

Different procedures and processes exist to inform researchers when conducting a systematic review and take the form of tools, guidelines and checklists to ensure quality and rigour. Most notably, the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement offers 27 checklist items that refer to the content of a systematic review or meta-analyses and can be used to both plan, conduct and present a systematic review. The PRISMA statement also includes a flow diagram which illustrates the flow of information through the different phases of the systematic review including initial identification of records, screening of records for relevance, determination of eligibility through the application of exclusion and inclusion criteria (and provision of the reasons for exclusions) and finally, the total number of studies included in the systematic review.

The PRISMA statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) was used to guide the systematic review conducted in this programme of research as it is designed not only for the evaluation of randomized control trials, but can also be used as a basis for reporting systematic reviews of other types of research. This was deemed particularly relevant as the majority of caregiving studies are cross-sectional and use varying psychometric and physiological tools to assess their participants, thus making it not possible to conduct a meta-analysis.

3.4.3 Mixed methods in the current research programme

It is these characteristics, along with the underlying epistemologies that guided the methodological decisions made in the current programme of literature. A systematic review (of both quantitative and qualitative literature) provided a rigorous overview of the current state of the caregiving literature and gave context to the current research, highlighting specific areas of research missing from the current body of literature. This method enabled the richness of prior qualitative research and the objectivity of prior quantitative research to provide a strong basis upon which to develop further research. A qualitative interview allowed for factors identified within the systematic review to be explored, as well as further exploration of a relatively understudied area. This provided guidance and a rich basis upon which to develop hypotheses and conduct a quantitative study of naturalistic field design, which though less personal and rich than qualitative data, provided objective conclusions based on statistical analysis and hypothesis testing, without influence of the researchers own interpretations of the data. Though each individual method contributes to the overall understanding of young carers, together they provide a bigger and more sophisticated picture, whereby previous literature is considered, the voices and experiences of young carers are represented in great detail and rigorous statistical analysis can provide objective conclusions about the population.

By evaluating and choosing these research designs within this programme of research, methods which complement each other and provide the most effective means to addressing specific research questions are used, rather than a limited approach which may only partially address the aims and objectives of the research (Johnson & Ongugbuzie, 2004). Ultimately, through a mixed methods approach, Bishop and Yardley (2008, pg359) argue a "richer and more complete description" of the topic at hand can be obtained than could be by using a single approach. Therefore, despite the drawbacks and cautions associated with mixed methods, and after consideration of the various approaches, with careful attention paid to the research questions, a mixed methods approach has been deemed the most appropriate and purposeful for this specific programme of research.

3.5 Mixed methods research designs and typologies

There are many different methods within quantitative and qualitative approaches, and there are a number of ways of combining these methods to create a mixed method research design. It is important to distinguish between the terms mixed model and mixed-method, where the former involves mixing specific methods from an individual approach to data collection within or across different stages of a research project and the latter involves the inclusion of a quantitative phase and a qualitative phase within a research project (Johnson & Onwuegbuzie, 2004). It is the mixed-method research design that is adopted in the current research programme, which allows for the collection of data that is both qualitative (in the form of photo elicitation interview) and quantitative (in the form of hair samples and questionnaires). As previously established, a pragmatic approach requires a researcher to carefully develop research designs that efficiently answer the research question at hand. Bishop and Yardley (2008) emphasise that a researcher should be able to cautiously consider and justify their choice to mix methods as well as identify clear aims which should be achieved via the individual aspects and approaches of the study.

The mixed methods research design used within the current programme of research is that of an exploratory sequential design, whereby a systematic review is followed by qualitative data collection and analysis which is then followed by quantitative data collection and analysis. This design was a fixed method research design, whereby unlike an emergent design, a predetermined research protocol is developed and implemented as initially determined (Creswell & Plano Clark, 2011). Six major mixed methods research designs have been presented which include sequential explanatory, sequential exploratory, sequential transformative, concurrent triangulation, concurrent nested and finally concurrent transformative design (Creswell & Plano Clark, 2011). Each of these designs involve the use and integration of quantitative and qualitative methods at different stages within or across research studies, or a specific programme of research. The fixed exploratory sequential design adopted for this research is particularly useful for the exploration of a topic which is considered

new, as is the case in the current programme of research where little literature exists surrounding outcomes and resilience factors in young carers. The use of a qualitative exploration of the experiences of this population allow the identification of potential protective resilience factors which can then be quantitatively measured.

A 'typology' notation system which was developed by Morse (1991) and has been consequently expanded, captures the different research designs diagrammatically and is used frequently throughout mixed methods research to illustrate the approach taken in an accessible way. The use of capital letters and notations 'QUANT' and 'QUAL' allow for the identification of the approach which has been has been given priority over and above the other, however it is possible for both approaches to be given equal priority (Creswell & Plano Clark, 2011). The use of a plus sign or an arrow within the typology acknowledges the order in which methods were used, either simultaneously (+) or sequentially (→) and larger studies can use both (Johnson & Onwuegbuzie, 2004).

The typology of the current mixed methods research design is presented below in figure 3.1 and indicates the levels of priority each stage is given and the sequential nature of the design. Typologies allow researchers to share a method of communicating about their research, provide an element of structure and can convey information in an accessible way. However, they have been criticised on the basis of their simplicity, particularly as they often omit important information such as the point of interface and the purpose of mixing data sets (Guest, 2013).

Mixed methods research is based on the principle that at some point, a researcher will mix two types of data by either combining them, having one build upon the other or embedding one within the other (Creswell & Plano Clark, 2011) and this takes place within a single research study or across a programme of research featuring multiple studies as is the case with the current research. The stage at which data are integrated is considered the point of interface (Morse & Niehaus, 2009). Creswell and Plano Clark (2011) highlight four ways in which data can be mixed; by merging the two data sets, by connecting the analysis of data from one study to a second set of data, embedding a data set within a larger research design and finally, using a framework to bind together data from two studies. The point of interface will be dependent upon the mixed methods design chosen, as for example, data from one study may inform the development of another and are therefore connected, or data may be integrated to provide an overall account of the findings in a way that is complimentary to each other (Creswell & Plano Clark, 2011). It is the former approach that has been chosen for the current research. Whichever method of mixing data is chosen, it is vital for researchers to be explicit about when and why data are mixed, not least for the purpose of transparency and replicability (Guest, 2013).

In order to address the criticism that typologies are simplistic and fail to identify the point of interface (Guest, 2013), the typology presented below is an extension of the classic exploratory sequential design typology and incorporates the contribution of the systematic

review method adopted in this research, but also highlights the two points of interface that exist, and the reasons for mixing the data.

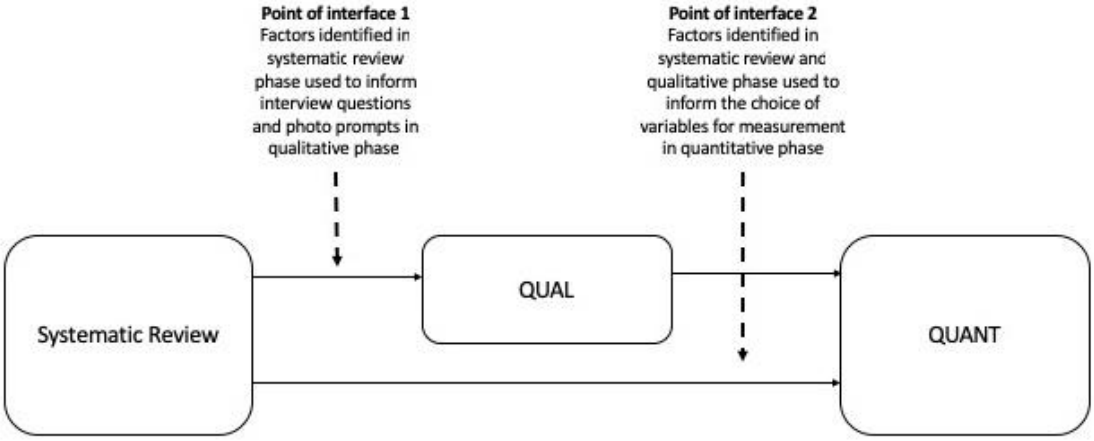

Figure 3.1 Typology of the current research programme

Though a multi-phase sequential design takes time to implement (Creswell & Plano Clark, 2011), for the purpose of foundational work in this area it is well suited and the most appropriate design for exploring the topic at hand. Creswell (2003) states that when researchers are not clear on the variables that need to be measured in a quantitative phase, a sequential exploratory design is the most effective. Due to the lack of research that currently exists in the field of young carers and resilience, a qualitative phase allowed for the investigation and identification of potential variables to measure in the quantitative study. Without the qualitative phase, variables measured in the quantitative study would have been based solely on findings from adult and elderly carers which may not have been appropriate or captured some of the unique experiences of young carers. Therefore, in this instance, the benefits of using a multi-phase sequential design outweigh the perceived drawbacks such as lengthy timescales.

3.6 Methods for data collection

Thus far, this chapter has discussed the overarching epistemology adopted in this programme of research, alongside the research design and mixed method typology. This chapter will now move on to discuss the different methods available for the collection of quantitative and qualitative data within the field of stress, resilience and young carers, providing rationale for the selection of the specific methods used in this research.

3.6.1 Methods for assessing stress

3.6.1.1 Physiological measures

For many decades, the measurement of physiological factors has been used in order to determine the physical impact of stress on the body (Foody, James, & Leader, 2014).

Biomarkers are an opportunity to elucidate how psychosocial stress can lead to a host of psychoneuroendocrine responses (An et al., 2015). Thus, a biomarker is defined as "a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes or pharmacologic response to a therapeutic intervention" (National Institute of Health Biomarker Definition Working Group, 2001, pg91).
There are individual biomarkers of stress that are used within research and for diagnostic purposes. In particular, studies have sought to measure multiple biomarkers in order to calculate a composite measure of stress, in line with the theory of allostatic load. As established, stress and allostatic load impacts numerous organ systems in the human body and by measuring biomarkers that represent these systems (see table 3.1) a composite score of total allostatic load can be calculated.

Table 3.1

Systems impacted by stress and examples of biomarkers used to assess allostatic load (adapted from Read & Grundy, 2012, pg. 3)

System	**Biomarkers**
Neuroendocrine	Adrenaline, noradrenaline, dopamine, cortisol, dehydroepiandrosterone, aldosterone
Immune	Interleukin-6, tumour necrosis factor-alpha, c-reactive protein, insulin-like growth factor
Metabolic	HDL and LDL cholesterol, triglycerides, glucosylated haemoglobin, glucose insulin, albumin, creatinine, homocysteine
Cardiovascular and respiratory	Systolic blood pressure, diastolic blood pressure, peak flow, heart rate/pulse
Anthropometric	Waist-to-hip ratio, body mass index

Within these biomarkers, the most frequently assessed stress related marker is the hormone cortisol (Read & Grundy, 2012; Vedhara et al., 2002) and this biomarker has been chosen as a measure in the quantitative phase of this research. There are different biological specimens that can be used to measure and assess cortisol production in humans, including blood, urine, saliva, and hair, each of which have their own benefits and drawbacks, particularly in relation to a population of young carers.

Saliva, urine and blood samples are all considered dependable measures of HPA activity and thus are common methods for assessing biomarkers of stress (Hellhammer, Wust, & Kudielka, 2009). Saliva sampling is the most popular method of obtaining cortisol for

analysis as it provides an opportunity to assess the biological impact of stress in a non-invasive way, in contrast to taking blood samples (An et al., 2015).

Cortisol has a robust circadian rhythm and diurnal pattern where it peaks approximately 30 minutes after waking and then declines over the course of the day, reaching its lowest point at approximately midnight (Lovell & Wetherell, 2011). A flattened diurnal cortisol slope, characterised by the initial peak but then a slower or less substantial decrease across the day, is an indicator of HPA axis dysregulation and is therefore considered to be less healthy as it shows that levels of the stress hormone continue to be present at high levels as the day advances (Chi et al., 2015). Sampling techniques such as saliva, urine and blood allow for the diurnal rhythm of hormones such as cortisol to be assessed, through repeated sampling at specific times over the course of one or several days, which can be time consuming and resource heavy (Hellhammer et al., 2009; Sauvé, Koren, Walsh, Tokmakejian, & Van Uum, 2007). Measurements of cortisol and other hormones via the methods of urine, blood and saliva can provide only a "snapshot indication of cortisol concentration" and therefore are particularly useful for assessing the impact of acute stressors rather than making interpretations about more enduring, chronic stressors (Noppe et al., 2014 pg97). In addition to this, due to the sensitivity of these biological specimens, there are a number of factors that can impact their reliability such as the consumption of food, specific medications, participation in exercise and alcohol consumption (Levine, Zagoory-Sharon, Feldman, Lewis, & Weller, 2007).

As caregiving is widely accepted as a chronic stressor, the usefulness of measuring cortisol via blood, urine or saliva for research with young carers is brought into question. Given that these methods are particularly sensitive to fluctuations and lifestyle factors, they require repeated collection of the specific biological specimen multiple times a day, for several days. This means that sampling places both increased cognitive and physical demands on carers who are already potentially facing restrictions on both these resources. Therefore, on the basis of practicality and the usefulness of saliva, urine or blood samples to assess cortisol levels within a chronic stress paradigm, it was not deemed appropriate to use these methods in a young carer population.

In contrast to urine, blood and saliva, the sampling of hair is a newer technique but one that has the support of previous research (Russell, Koren, Rieder, & Van Uum, 2012) and offers a more stable assessment of biomarkers such as cortisol. It has been concluded in recent years that hair cortisol concentration levels can be readily and reliably measured, including in younger populations such as children and young people (Noppe et al., 2014). Hair grows at approximately 1cm per month, and can offer a retrospective view of cortisol production in the body (Sauvé et al., 2007). Given that caregiving is a chronic stressor, this method is particularly useful in the assessment of cortisol levels in this population. Collection of hair is considered non-invasive, painless and efficient with regards to time (Sauvé et al., 2007) particularly as for a cross-sectional study, only one sample of hair is required for analysis and the technique requires

no formal training or medical clearance. With this in mind, compared to repeated saliva, urine or blood samples (the latter of which require specific training and medical clearance, and have the potential to be distressing), hair samples are deemed the most appropriate method for the assessment of cortisol in the context of the chronic stress in a population of young carers. Furthermore, hair samples, unlike saliva, blood or urine, do not require refrigeration or freezing, and can be stored at room temperature (Noppe et al., 2014). Given the challenges faced in young carer research (discussed later in this chapter) the convenience of storing samples allows for flexibility in data collection times and locations.

Studies have been conducted to establish ranges of hair cortisol concentration in healthy children, and to determine any factors which may impact the reliability of the measure (Suave et al., 2007). To date, it has been found that puberty, gender, natural hair colour, hair washing frequency, hair product use and BMI do not impact cortisol secretion in hair (Noppe et al., 2014). Hair dye, bleaching and perming however have been found to influence cortisol levels (Suave et al., 2007). Identification of these influential factors allow them to be controlled in scientific investigations and for the explanation of outliers within statistical analyses.

A final source of rationale for the use of hair samples comes directly from young carers themselves who were informally consulted on their preference of sampling technique. Hair samples were preferred by young carers for a number of reasons, including them being less painful and clinical than blood draws, less time consuming than saliva, blood or urine samples and the perception that hair samples were more hygienic than saliva or urine.

3.6.1.2 Questionnaires

Standardised questionnaires have been developed to assess stress in various populations, however not all questionnaires are suitable for child and youth populations. The measures used in the current research will now be described and justified.

3.6.1.2.1 Social Readjustment Rating Scale for Teens (SRRS)

The Social Readjustment Rating Scale was developed by Holmes and Rahe (1967) to provide a standardised measure to assess the impact of stressors or life events such as illness, getting married or bereavement. Unlike some measures, this scale places a value on each life event based on severity and provides an overall score of experienced stressors in the past year. Though originally designed for adults, a ‘non-adult’ 39 item version exists which can be completed by children, adolescents or their parents. This measure was chosen for the current research as despite its age, it is a consistently well-validated and reliable measure of life events as evidenced in a review assessing its use (Scully, Tosi, & Banning, 2000). The measure also provides an overall score of major stressors rather than a simplistic total of individual events.

3.6.1.2.2 Perceived Stress Scale-10 (PSS-10)

Similar to the SRRS, the Perceived Stress Scale (Cohen, 1994) was originally developed and intended for use with adults. It has since been confirmed as a useful and valid measure for use in numerous populations including school aged children (Al Kalaldeh & Shosha, 2012). The 10-item PSS assesses the extent to which an individual appraises events in their life as stressful based on the month prior to completion. The PSS-10 has been shown to demonstrate high internal consistency (Cronbach alpha = .89) and good convergent validity in undergraduate students (Roberti, Harrington, & Storch, 2006). This questionnaire was chosen as it was deemed the most appropriate for the assessment of perceived stress in this population, and is relatively short in length, reducing the potential for respondent fatigue.

3.6.2 Methods for assessing psychosocial factors

Psychosocial factors are typically assessed via standardised questionnaires which have been validated for use in a specific population, such as young children or adolescents. Standardised measures are used in the current research to assess coping, resilience, benefit finding, family support, social support and attachment to pets. These factors were chosen to be measured in the second empirical study of this research due to the evidence presented in previous literature and factors identified within the qualitative stage of the research.

3.6.2.1 Questionnaires

The questionnaires chosen for the quantitative phase of this research will now be described and discussed in relation to the current research.

3.6.2.1.1 The Child and Youth Resilience Measure-28 (CYRM-28)

As discussed previously, defining and measuring resilience is challenging, and therefore measures of resilience must be carefully considered and cautiously interpreted. The Child and Youth Resilience Measure was developed to allow researchers to assess the level of resources (individual, relational, communal and cultural) that are available to an individual and may enable their resilience (Ungar & Liebenberg, 2011). This measure therefore reflects the theory surrounding resilience and accounts for individual, peer, family and community resources as identified by Rutter (1979) and Luthar, Cicchetti and Becker (2000). Numerous versions of this measure exist which can be used in children, young people and adults of all ages. There is also a proxy version allowing a third party to provide data for a young person. The CYRM-28 has good overall validity as assessed in a systematic review (Windle et al., 2011). Since then it has also shown validity and internal consistency in Canadian Youth (Liebenberg, Ungar, & van d.V.jver, 2012) and a sample of at-risk New Zealand Youth (Sanders, Munford, Thimasarn-Anwar, & Liebenberg, 2017). For the purpose of this research, the 28-item CYRM was chosen

as it assesses a range of resources, has been validated for use with young people and is considered a reliable and valid self-report instrument (Ungar & Liebenberg, 2011).

3.6.2.1.2 Kidcope-11

The most established and validated measure of coping for use in children and adolescents is the Kidcope (Anthony Spirito, Stark, & Williams, 1988). Though there are other measures of coping which do exist, such as the COPE (Carver, Scheier, & Weintraub, 1989) and the Responses to Stress Questionnaire (Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000), the Kidcope assesses coping across 11 domains: problem solving, positive emotion regulation, cognitive restructuring, seeking social support, distraction, negative emotion regulation, social withdrawal, wishful thinking, self-criticism, blaming others and resignation. The version for children aged 7 to 12 years includes 15 items, whereas the version for adolescents includes 11 items and has a higher reading level (Spirito, Stark & Williams, 1988). This scale was found to have high test-retest reliability (Spirito et al, 1988) and was shown to be valid in studies with children (Spirito, Stark, & Tyc, 1989; Spirito, Stark, Gil, & Tyc, 1995). The 11-item version was selected for this research for a number of reasons, including fewer items whilst still assessing a variety of coping qualities to reduce participant fatigue, and also because it has been validated for use in an adolescent population.

3.6.2.1.3 Benefit Finding Scale for Children (BFSC)

A number of scales exist to assess benefit finding in children and young people, including the Benefit Finding Scale for Children (Phipps, Long, & Ogden, 2007) which was developed from studies involving a childhood cancer population. This scale is a brief measure of 10 items which are answered on a 5-point likert scale ranging from 'not at all true for me' to 'very true for me'. The benefit finding scale for children was developed on the premise that adverse experiences during childhood could be beneficial and that these experiences need not necessarily be traumatic in nature, but could involve what is considered low-level distress. The BFSC has been used effectively in a number of populations including survivors of childhood cancer (Michel, Taylor, Absolom, & Eiser, 2010) and children with type 1 diabetes (Huston, Blount, Heidesch, & Southwood, 2016). The scale showed good validity and excellent internal consistency (Cronbach alpha .834) in a population of children with cancer with whom it was first developed (Phipps et al., 2007). Although the Benefit Finding in Child Caregivers Scale (BFCCS; Cassidy & Giles, 2013) exists, the Benefit Finding Scale for Children was chosen for the purpose of this study. Given the specific nature of the items in the BFCCS such as 'Having an ill or disabled relative helps me think about the good things in life' it was deemed inappropriate for the collection of comparable data from both carer and non-carer sources, as these specific items would not have been relevant to young people not providing care. The BFSC however is a general scale that can be applied to numerous different situations.

3.6.2.1.4 Wills Family Support Inventory (WFSI)

The Wills family support inventory is a 15-item measure which assesses emotional and instrumental family support (Wills, Vaccaro, & McNamara, 1992). Items are answered using a four-point scale ranging from 'not at all' to 'very much' with total scores reflecting overall family support. The scale was developed for use with adolescent substance use, but has been applied to maltreated children (Wong et al., 2009), disordered eating (Lai, Tang, & Tse, 2006) and exposure to violence (Youngstrom, Weist, & Albus, 2003). The WFSI was reported to be a valid measure with good internal consistency upon its development for both emotional (.74) and instrumental (.81) support (Wills et al., 1992). Since initial development, the scale has shown Cronbach's alpha's for instrumental and emotional support of .82 and .84 respectively (Lai et al., 2006). This scale was used for the current research alongside an assessment of social support received from friends (see below). The family support inventory was chosen as caregiving is typically experienced within the family system and it was important to assess social support on specific levels rather than more generally, to draw conclusions and further unpick the impact of social support on young carers. Furthermore, compared to other family support measures that exist such as the Perceived Social Support from Family Scale (Procidano & Heller, 1983) the WSFI had only 15 items which was appropriate in order to prevent participant fatigue.

3.6.2.1.5 Perceived Social Support from Friends (PSS-Fr)

The Perceived Social Support from Friends scale (Procidano & Heller, 1983) is a 20-item measure answered with either 'yes', 'no' or 'don't know' and was developed in order to tap into specific social support dimensions. The measure has been used in research with participants of all ages ranging from children, adolescents and adults and across a wide range of populations and topics including adolescents with diabetes (La Greca et al., 1995). The scale demonstrated excellent internal consistency when first developed (.88, Procidano & Heller, 1983) and has since demonstrated Cronbach's alpha values ranging from .77 to .92 in other samples (La Greca et al., 1995; Lyons, Perrotta, & Hancher Kvam, 1988). This scale was chosen as it has demonstrated reliability in previous studies and has been used in adolescent populations.

3.6.2.2 Interviews

Semi-structured and structured interview protocols exist to assess stress, coping and resilience in young people, however most often these involve a proxy response, whereby a parent or teacher answers the questions on behalf of the child or young person and many are focussed on psychopathology and diagnostic techniques (Kazak, Stuber, Barakat, & Meeske, 2008). Whilst this may be effective in some cases, many argue that it is important to consider

the voice of young people and give them the opportunity to share their own story and experiences surrounding a specific topic (Ford et al., 2017), in this way they are fully represented in research that is essentially about them. Luthar (2000) argues that researchers have a duty to account for the voices of young children in order to understand their circumstances and lived experiences, rather than depending on the view of third parties. With reference to the specific topic of the current research, an Australian Government report (Shean, 2015, pg31) highlights that the voices of young carers "remain somewhat absent" within resilience research and it is important to not assume that individual's external to a young person can offer more insight into their lives than the young person themselves.

In order to collect information about the experiences of children or adolescents from the individuals themselves, and facilitate honesty, free expression and creative thought, it is important to use an appropriate method (Mandleco, 2013). There are many techniques used to elicit responses during interviews with children and young people and researchers have a responsibility to choose methods that answer research questions but are also appropriate for the target study population, especially when involving children and young people Cappello, 2005). Mauthner (1997) encourages a child centred approach considering children as subjects rather than objects of research.

Methods such as diaries, drawings, video diaries and photographs alongside a standard and more classic interview format have been found to be especially useful for research with children and young people. In particular, photo elicitation has been considered engaging and enjoyable as it allows participants to portray specific moments in their lives that might be overlooked in traditional interviews (Jorgenson & Sullivan, 2009; Mandleco, 2013). Photo elicitation involves the use of photographs to guide an interview process and to elicit responses from participants about a specific topic, this process is typically used in semi-structured interviews to allow for exploration of the meaning and story behind photos beyond a regimented structured interview schedule.

Different forms of photo elicitation exist and range from researcher-driven, whereby the researcher provides photographs for discussion in interviews, and auto-driven, whereby participants themselves take photographs for discussion based on a number of prompts or a single objective (Clark, 1999). The former is considered useful when previous literature or research exists on a topic and therefore photos can be provided by the researcher on this basis. The latter however is more useful for exploratory investigations where little to no previous literature exists to inform possible photos and therefore there is no basis for the provision of relevant and suitable photos. Auto-driven photo elicitation was chosen for the current research due to the lack of previous literature, the exploratory nature of the research question and also to promote autonomy for the young participants.

It is argued that photo elicitation can enable deeper understanding of topics as photos require more brain capacity than words alone (Harper, 2002). Additionally, understanding is

rooted in the image itself, closing the gap between researcher and participant, where the content of the interview is placed within a mutual space (Harper, 2002). Furthermore, auto-driven elicitation allows children to choose which images they would like to discuss and is therefore particularly empowering for children and adolescents engaging in research about their lives (Mandleco, 2013). Using photos allows the researcher to "invoke comments, memory and discussion in the course of a semi-structured interview" (Banks et al, 2001, pg87). By doing so, the object of the research becomes the photos rather than the participants, thus promoting autonomy, competence and resilience (Carter et al., 2015). It was felt that these were important qualities to promote in research with young carers given the restrictions and lack of autonomy they might face in their daily lives.

Photo-elicitation with children has the potential to address the power imbalance that can exist within research and encourage a more comfortable, safe and open atmosphere in which discussion and disclosure can take place (Mandleco, 2013). Given the at times sensitive nature of youth caregiving and the desire to promote autonomy in a young carer population, this method was deemed appropriate for the current research.

To date, no studies have employed this method with young carers, however it has been widely used with young people in order to explore issues such as preparation for school in low-income families (Miller, 2016), online and offline peer interactions (Pabian et al., 2018) children's grief (Stutey, Helm, LoSasso, & Kreider, 2016) and perceptions of adolescents with diabetes (Hanna, Jacobs, & Guthrie, 1995). The method has also been used in populations such as the homeless (Percy, 1995), children with mobility impairments (Aitken & Wingate, 1993) and siblings of children with Down syndrome (Rampton et al., 2007), indicating the method's wide applicability and effectiveness in addressing numerous topics including those of a sensitive nature. Though photo elicitation can be more costly, time consuming and demanding than a traditional style interview (Ford et al., 2017) it is an accessible way to collect data about abstract ideas such as feelings, emotions or possible scenarios (Mandleco, 2013) and is described as a fun technique which is easy to master and useful for children to capture their thoughts, feelings and experiences in a way that is accessible to adults conducting research (Ford et al, 2017).

3.7 Analysing and integrating mixed methods data in the current research programme

3.7.1 Qualitative analysis

Qualitative data can be analysed using manual techniques (by hand) or using specifically designed computer software such as NVivo (QSR International). Due to the diverse nature of qualitative methods and the subsequent qualitative data that is collected there are a number of different analytic approaches which include interpretative phenomenological analysis (IPA), grounded theory, discourse analysis, conversation analysis, narrative inquiry and finally

thematic analysis (TA). Often, each analytic approach can be further divided into different approaches such as inductive, deductive, experiential or constructionist. Inductive analysis involves a 'bottom up' approach whereby the findings drawn from the data are strongly associated to the data themselves and are not informed or driven by a researcher's prior theoretical knowledge of the area ahead of data analysis, therefore this approach benefits from the researcher not engaging with the literature until the later stages of analysis (Braun & Clarke, 2006). Conversely, deductive analysis involves a 'top down' approach whereby findings are considered to be theoretically driven, that is, the analysis itself is guided by a researcher's prior knowledge of the literature and theoretical background, requiring researchers to engage with the literature prior to analysis which can sometimes support any aims to fit findings into the pre-existing knowledge (Braun & Clarke, 2006). Due to the existence of a relevant resilience theory, developed and applied to a caregiving population, the qualitative phase of the current research programme adopted a deductive TA as it is considered to be a flexible, diverse and easily accessible approach which forms the foundation of qualitative analysis and allows researchers to identify, analyse and report themes that are drawn from the data in line with pre-existing theoretical knowledge (Braun & Clarke 2006). Themes portray and summarise patterns within the data which are considered relevant or interesting in relation to the overall research question being addressed. In order for a pattern to be deemed a theme it does not necessarily need to feature heavily or repeatedly within the data set, however it must represent important and key aspects of the data. Braun and Clarke (2006) emphasise that the analyst must make judgements to determine what a theme is and be consistent in these decisions, ensuring that identified themes are a truthful representation of the entire data set.

Braun and Clarke (2006) also argue that it is vital for researchers to be clear about why they are proceeding with a TA, make a number of analytical decisions prior to data collection and to review these decisions throughout the process of analysis. The primary decisions involve determining what is considered a theme, whether a rich description of the data set is required or a detailed account of a specific aspect of the data, choosing between an inductive or deductive approach, deciding whether themes will be identified at a semantic (explicit) or latent (interpretive) level and finally the epistemological stance that will be taken. Additionally, it is important for researchers to develop two types of questions with different functions, the first is the overall research question or questions that underpin and guide the project and the second are the questions that participants answer when qualitative data are collected via means such as interviews or focus groups. The elements of TA, and the lines of enquiry proposed above, were considered and discussed prior to, during and after data analysis to ensure that analysis was conducted in line with Braun and Clarke's recommendations.

TA is summarised as a refinement process which takes place across various stages of the analysis and requires a recursive approach, often involving moving backwards and forwards between various aspects of the data set at different times during the process (Braun & Clarke,

2006). This took place within the current qualitative analysis, whereby different aspects of the data were explored, revisited and considered, before final themes and conclusions were drawn.

The overall process of conducting a TA is summarised into six phases by Braun and Clarke (2006) and include: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and finally, producing the report of findings. It is unusual to begin analysis without any prior familiarisation of the data as often researchers have collected the data themselves, as was the case in the current research, however further understanding of the data can be gained through additional steps of preparation for analysis. Riessman (1993) argued that transcription of verbal or visual data such as audio files or observation films can be a useful process which aids the familiarisation with the data, therefore all transcription of audio files was conducted by the primary researcher (TH) who also conducted the main analysis. Furthermore, Braun and Clarke (2006) encourage active reading or viewing of transcripts or visual data in a way that is not rushed, as overall analysis outcomes depend on the level with which the researcher is familiar with the data they are analysing. Given this, flexible timelines were developed to ensure the primary researcher had sufficient time to read transcripts thoroughly, make initial notes and conduct the final analysis, taking into account the potential for revisiting transcripts and elements of analysis throughout the process.

Familiarisation with the data continues throughout the whole of the analysis process due to the various stages involved. The second phase, generating initial codes, involves labelling as many aspects of the data set as possible which are interesting and relevant in terms of the research question and it is advisable to work in a systematic manner through the entire data set to ensure overall consistency (Braun & Clarke, 2006). The action of coding allows researchers to begin organising the data in a way that makes sense and is meaningful (Tuckett, 2005). Initial coding was conducted by hand, by the primary researcher, with the specific research question, guiding theory, findings of the systematic review and future quantitative study in mind.

The third phase of TA requires the researcher to begin searching for themes within the list of codes that are generated and assemble data extracts (quotes) that are relevant and support the identification of these particular themes. This process was conducted digitally and involved creating a database (using Microsoft Excel) to collate codes and themes alongside the relevant and appropriate supporting data extracts. Once initial themes have been developed phase four begins whereby identified themes are reviewed and it is during this stage where some themes may be deemed inadequate due to insufficient supporting data or others may become subthemes within a larger over-arching theme. There are two levels of review and refinement within this phase which require the researcher to first review at the level of the data extracts which have been coded and second to judge the legitimacy and consistency of individual themes in relation to the overall data set (Braun & Clarke, 2006). At this stage, themes least relevant to the research question were considered for exclusion from the overall presentation of the data as addressing the research question was deemed the primary aim of the qualitative study. By the

end of phase four of analysis it should be clear what the main themes and subthemes are and how they relate to the research question being investigated. The penultimate phase is when the identified themes are defined and given names, it is at this point that some changes may be made to themes with regards to whether they constitute a strong enough pattern throughout the data or whether they need to be removed, reconsidered or collapsed into another theme (Braun & Clarke, 2006). The final phase of the analytic process is that of writing the report of findings, whereby the researcher is required to provide a detailed analysis and account of the themes in a concise, coherent manner with the support of relevant and illustrative quotes from the original data set.

There are a number of strengths to this method including its use in different approaches such as essentialist (whereby the reality of research participants is reported) or constructionist (whereby experiences are investigated as the outcome of societal values and discourse) (Braun & Clarke, 2006). It was the former approach that was taken in the current research, whereby the experiences of participants as they described it, was deemed to be reality, and thus formed the basis of interpretations and conclusions surrounded the data. TA was chosen for the qualitative aspect of the current research programme due to its flexibility and accessibility but also because Braun and Clarke (2006) recommend this method, as though TA can lose some depth and complexity compared to other qualitative analytical approaches, it still offers a rich overall description which allows for interpretation and is particularly useful for investigations which are typically underserved with regard to research and published literature, as is the case with young carer research and the qualitative phase of this research programme.

3.7.2 Quantitative analysis

Quantitative data analysis typically involves statistical programmes such as SPSS (Statistical Package for the Social Sciences) which allows descriptive and inferential statistics to be used to explore relationships between different elements of the data. Before statistical tests can be run, it is important to carry out data screening to check for outliers as well as assess for the assumptions that need to be met in order for statistical analyses to be reliably conducted. The quantitative data collected in this research, including questionnaire responses and hair cortisol concentration, will be analysed through the use of statistics (greater detail of data screening, assumptions and analytic strategy is presented in the quantitative chapter of this thesis, Chapter 6).

In order to determine differences between matched groups (young carers and non-carers) on the variables of perceived stress and hair cortisol concentration, independent samples t-tests will be used which require the assumptions of independence of observations and normal distribution to be met, alongside the checking of outliers and for variables to be measured at the interval or ratio level. This test will compare the means of the dependent variable (perceived

stress or hair cortisol concentration) and determine whether there is a significant difference between young carers and non-carers and if so, what the strength of this difference is.

To explore the relationships between perceived stress, hair cortisol concentration, resilience and benefit finding, Pearson correlation analyses will be used which require the assumptions of linearity, normality and homoscedasticity to be met, alongside the absence of outliers and for variables to be measured at a continuous level. Pearson correlation allows a co-variate to be entered and tests the relationship between two variables, and where a relationship is present, determines the significance, direction and strength of it. A mediation analysis will be performed following the correlations to establish the impact of resilience and benefit finding as mediating factors of the relationship between perceived stress and hair cortisol concentration.

To explore the impacts of psychosocial factors on the outcomes of resilience, perceived stress and hair cortisol concentration, hierarchical linear regression will be used, which requires the assumptions of independence of observations, normality, linearity and homoscedasticity to be met, alongside the absence of outliers and for variables to be measured at the interval or ratio level. Hierarchical regression analysis allows for covariates to be entered into the regression model and for each independent variable to be assessed for its contribution towards the variance in the dependent variable. Moderation analyses will be conducted to determine whether the relationship between perceived stress and social support accounts for any of the variance in hair cortisol concentration.

3.8 Practical challenges of research with young carers

There are challenges in researching young people, some of which are unique to a population of young carers. This chapter will now discuss these challenges with specific reference to those faced in this programme of research, and offer reflections on attempts to address them.

3.8.1 Age appropriateness and accessibility

For many years, the capability of children to participate in research was doubted, however in recent decades researchers have argued the importance of not only including children in research, but also giving them an opportunity to speak for themselves, rather than using vicarious means of collecting data such as parent or teacher interviews (Einarsdóttir, 2007). Children are considered to be self-aware and the most knowledgeable about their own personal experiences, however including them in research does not come without challenges for the researcher. In order to overcome these challenges, the first step is to use an appropriate research method which engages the young person in the process of research, but also provides them with the support and confidence to express thoughts, feelings or opinions (Einarsdóttir, 2007). This includes the format that data collection methods take but also the way in which a researcher might approach an interaction with a young person. Gollop (2000) proposed that

instead of characterising the data collection process as an interview, framing it as a conversation, in which the researcher actively listens, gives the young person the opportunity to speak freely in addition to building rapport for the collection of valuable data. With this in mind, the qualitative stage of this research sought to engage young carers through the method of photo elicitation but also framed the discussion of photos as a 'chat' whereby the researcher came to 'talk to', rather than interview, the young person so that they could tell the researcher about the photos they had taken and what they meant to them. For some participants who were as young as five years old, the prospect of talking about the photos was more accessible and tangible than the suggestion of an interview.

A further challenge of research with children includes that of developmental progression and the understanding of specific concepts. In order to make research accessible for young people, it is important that materials are appropriate in terms of language and the concepts used (Einarsdóttir, 2007). Materials in the current programme of research included information sheets, consent forms, debrief sheets, questionnaires and the prompts used for the photo elicitation study. These materials were carefully chosen to reflect the developmental ages of those they were aimed at, making them as accessible and understandable as possible for young participants, whilst also not undermining or patronising older participants. In some instances, it was appropriate to develop separate materials for different age groups, and for the qualitative stage of the research programme separate information sheets were designed for those of primary school age and those of secondary school age. Furthermore, during the interview itself, where necessary, questions were phrased slightly differently depending on the young person's age and perceived level of understanding. Those who were particularly young were encouraged to ask for clarification or to alert the researcher if there was anything they did not understand and this occurred during a number of the interviews.

3.8.2 Recruitment and gatekeepers

The recruitment of children in qualitative health research has been demonstrated to be a challenging and slow process (Huang, O'Connor, Ke, & Lee, 2016; Shaw, Brady, & Davey, 2011). This is particularly attributed to the necessity to recruit young people via gatekeepers; those who live or work directly with them. This process requires researchers to liaise with the individuals and encourage them to facilitate the participation of young people in the research project. Gatekeepers typically comprise of adults such as school teachers, charity staff, hospital managers, social workers and parents (Huang et al., 2016). Within research, children and young people are considered a vulnerable population, and in some cases additional levels of vulnerability are present, such as those who are in care, have experienced mistreatment or are young carers. As a result, gatekeepers can be understandably critical of research projects and may question the usefulness and importance of the proposed research in addition to the activities involved in participation (Huang et al., 2016). In particular, issues of safety, ethics and

burden can be raised (Shaw et al., 2011). Though critiques or declined interest can slow down or halt the recruitment process, these interactions can offer valuable information and feedback for future recruitment endeavours, as was the case in the current programme of research. In terms of the qualitative study, questions were raised regarding the use of photographs in the public domain by gatekeepers, and when the rules surrounding this were explained (see ethics section below) issues were resolved. Furthermore, two organisations considered the hair sampling technique to be invasive for young people, particularly in the early stages of recruitment. This led the researcher to have their own hair sample taken in order to show participants how much hair is required, but also to record a video demonstration of the hair being taken to fully illustrate what was required. In addition to this, it was emphasised that participants could withdraw from having their hair sample taken right up until the moment of taking the sample. Following these clarifications, only two organisations declined participation on the basis of the hair sampling requirements. The feedback given from organisations shaped the future recruitment process and enabled more successful recruitment of young carers and young people.

A key gatekeeper for research with children and young people are schools, which have been criticised for being slow to recognise and accept that there are young people within their student populations who are providing care for a family member in their own home (Andrew & Becker, 2000). Although schemes such as 'The Young Carers in Schools Award' (Children's Society & Carers' Trust) have sought to empower schools to identify and provide for young carers, many remain resistant. This causes further challenges in recruitment as 'gatekeepers' to this population such as head teachers or pastoral support, could be helpful in connecting researchers and young carers to enable research to take place, but do not realise they are in a position to do so, as they are not aware of, or have not yet identified young carers within their school. This was indeed the case during this programme of research whereby letters or emails were sent to 50 schools in the South West of England informing head teachers and pastoral support about the research and inviting them to be involved. Two schools were involved in recruitment and data collection. Two schools, the first of which had approximately 1200 registered students and the second approximately 1000 students, responded to invitations stating that they did not have any young carers within their student population. Statistically, this is unlikely, therefore it begs the question as to whether there were indeed no young carers within these schools, or whether the school had not yet identified the young carers within their student population. This demonstrates a lack of awareness surrounding young carers within schools and causes challenges when researchers seek to recruit for young carer research.

Ultimately, when dealing with gatekeepers of potential research participants, it is important to ensure that there is transparency surrounding what the research will require of participants but also what the gatekeepers themselves will be required to do, as many gatekeepers to children and young people are often concerned about their own busy schedules

and workload (Huang et al., 2016). In order to overcome this in the current research, a clear timeline was provided with suggestions of how the research process may proceed, but it was emphasised that this process was open for discussion in order to facilitate the research in a way that was most convenient and accessible for those supporting the project. This meant that only three carers' centres declined interest on the basis of lack of time, resources, busy schedules or heavy workloads.

3.8.3 Developing rapport

Developing rapport is important in research with people of all ages and there are a number of factors to consider when conducting research with children and young people. The physical location and atmosphere in which research takes place can impact the way young people interact with researchers and answer the questions asked, whether through interviews or formal questionnaire measures. Shaw, Brady and Davey (2011) recommend that creating a relaxed atmosphere before data collection begins is important, especially with interviews which can be of a personal or sensitive nature. In order to create this atmosphere, children and young people who took part in the interview stage of the research were invited to choose the location in which to be interviewed. This meant that the majority of interviews were conducted in the participants own home, with another being conducted at the university, and another conducted within a room at a carers' centre. In addition to this, in order to develop rapport at the start of the interviews and with the aim of creating a comfortable atmosphere, young people were given the opportunity to look through their photos in their own time, prior to the interview, before any recording equipment was set up. This meant they could be reminded of the photos they had taken and begin to prepare themselves for the topics which might be covered in the interview. For the quantitative study participants typically completed questionnaires in their own home, however many of the young carers were attending an event at the carers organisation they accessed and therefore had familiar adults and other young carers surrounding them, adding to a comfortable atmosphere.

A final element of creating rapport, was that of the researcher disclosing their own status as a former young carer. Though there are no formal ethical guidelines or recommendations surrounding personal disclosure, it is an element of research that needs to be carefully considered before taking place (Oakley, 2013). Some researchers recommend that disclosure should always be made (Reinharz & Davidman, 1992) and some argue that although it can assist in the development of a trusting interviewer-interviewee relationship, it should only be done when necessary (Labaree, 2002). Disclosing status can have implications for the development of rapport, but it can also have implications for the research itself, particularly in qualitative interviews. Indeed, as a former young carer, it was important for the researcher to ensure that this 'insider' knowledge did not cause assumptions to be made about those taking part in interviews for example leading to a lack of follow up on certain points due to an implicit

understanding between both interviewer and interviewee. In order to manage the issue of disclosing personal information, it was decided that unless directly asked during the process of recruitment, obtaining consent, interviews and debriefing for the qualitative studies, personal disclosure would not be made. More than half of the interview participants, or their parents enquired as to the researcher's caregiving status, one prior to the interview and five following the completion of the interview. The researcher was acutely aware, and included prompts on the interview schedule for their own use to remind them of the importance of following up on points and eliciting as much information as possible from participants, rather than making assumptions or taking information for granted. During the quantitative phase of the researcher, the researchers' status was disclosed at the recruitment stage in order to promote the study and the motivations of the researcher, particularly as this stage of the research was more invasive than the interviews.

3.8.4 Increased demands on young carers

Due to the nature of their lives, young carers are often busy, with restrictions already placed upon their time (Pakenham et al., 2006). Therefore, involvement in studies such as those carried out in this programme can be quite an undertaking for young people who are not only facing restrictions on their time but also managing a high cognitive load due to their caregiving responsibilities, social activities and education. With this in mind, research protocols were developed in line with informal feedback from young carers to be as streamlined and efficient as possible. Einarsdóttir (2007) notes that it is rare for children to be given the opportunity to be involved with the planning of research or the development of research protocols, therefore it was considered important to seek the opinions of young people, particularly young carers, at various stages of the research development phases. For example, after explaining the different methods of measuring cortisol to a group of young carers, many specified that hair samples would be the most preferred method due to the minimal time required in contrast to saliva samples which would not only place demands on time due to the number of samples required over a number of days, but also increase cognitive load with the requirement to remember instructions involving food and drink consumption and the timing of samples.

3.9 Ethical considerations

Conducting research with children and young people is often perceived as risky for both participants and researchers, primarily due to the vulnerability of children in comparison to adults and the practical challenges such as those outlined above (Carter, 2009). Despite the methodological and ethical challenges that surround research with children and young people, excluding them from studies which explore aspects of their experiences makes them increasingly vulnerable and does little to acknowledge their agency and right to participate (Ford et al., 2017). With this in mind, ahead of conducting the current programme of research,

ethical considerations were made and ethical approval was granted from the Psychology Ethics committee (qualitative study) and the Social Research Ethics Council (quantitative study). Skelton (2008) argues that specific approaches need to be taken when working with children and young people. The approaches taken for the current research are described below.

3.9.1 Consent & withdrawal

Obtaining informed consent means research participants take part in the study fully aware of what is required of them and their rights at all times during the process of research (Einardottir, 2007). The current research programme informed young people about what their involvement would require and their rights to withdraw, in addition to providing an opportunity to ask questions about the research before verbal and written consent was requested. Those under the age of 16 years were also required to obtain written parental consent to take part and information was provided in written, video and verbal formats to ensure parents understood the research their child wished to be involved in.

When conducting research with children and young people, the power imbalance between the adult researcher and the child participant can have implications for informed consent, whereby children may find it difficult to explain to or tell a researcher that they do not wish to be involved with the research or that they may want to withdraw from the study during data collection (Einardottir, 2007). Therefore, it is recommended that the consent of children and young people should not be considered a single event and instead, informed consent should be an ongoing and open process which is consistently and constantly reviewed throughout the entire process of research involvement (Alderson, 2008; Shaw et al., 2011). The current research ensured that the young people taking part were given multiple opportunities to withdraw from the study and emphasis was placed on the right to withdraw at any time. Initial explanations about each study took place and young carers were given time to consider their participation without the presence of the researcher, meaning that if they did not wish to take part, a parent or caregiver could relay this message, reducing the pressure that a young person may feel to be involved. There were two young people who withdrew from the qualitative study after being provided with cameras, and three people who declined full participation in the quantitative study and a small number of participants who declined a hair sample but completed the questionnaire. This provided assurance that encouraging young people to only take part if they completely understood what was required of them gave them the opportunity to decline participation if they wished.

3.9.2 Confidentiality and anonymity

It is important for research participants to know that their identity, or any identifiable information shared during research will not be disclosed beyond the research team, in order to prevent embarrassment or harm (Einardottir, 2007). Due to the nature of the photo elicitation

method used in this research programme, special considerations surrounding confidentiality needed to be made for not only the participants, but also individuals around them. Researchers have a duty of care to protect those who may appear in photos when this method is used for qualitative research (Ford et al, 2017). It was important for parents and children to know exactly how photos may be used in the future and conditions were set surrounding the content of the photos and how they may be used. Children in this study were clearly informed that whilst they were able to take photos of other people, they must do their best to obtain their consent where possible and appropriate. They were also informed that whilst photos containing people or identifiable information such as school uniforms or road names could be discussed with the researcher, these photos would not be used for presentations, publications or any other research related activities. Young people were also given the opportunity to specify photos that they did not wish to be used for these purposes, in line with photo elicitation research conducted by Ford et al (2017).

3.9.3 Risk of harm or distress

The research designs for this programme of research did not pose any risks of harm to participants, however, as is often the case with interviews of a sensitive nature, it was noted that some questions may cause emotive responses. The researcher was prepared for these instances and on one occasion where a participant became emotional, the interview was paused, a break was taken and the young carer was asked if they would like to continue. Nobody withdrew during qualitative data collection.

In order to further protect young people and demonstrate commitment to this, the researcher carried a full Disclosure Barring Service (DBS) check, to show to gatekeepers and young people when asked and also attended a Mental Health First Aid training prior to data collection.

Finally, the risk of harm to the researcher was considered, and when data collection was conducted in the homes of participants, the University of Bath lone working policy and fieldwork guidance were followed. Measures for obtaining assistance in an emergency were put in place and there was a system for verifying the whereabouts and safety of the researcher via a checking-in system.

3.9.4 Reimbursement of participants

A final ethical issue that required consideration was that of reimbursing participants for their time and involvement in the research. Whilst some researchers argue that reimbursing young people for their involvement can be coercive and may hinder the process of informed consent (Crivello, Morrow, & Wilson, 2013), others maintain that it can benefit recruitment and retention (Greene & Hogan, 2011). Shaw, Brady and Davey (2011) state that children and young people should receive appropriate remuneration and recognition for their involvement in

research and suggest that rewards such as high street vouchers or a memento of research participation are suitable. Given this, for the first stage of this research young carers were able to keep copies of the photos they had taken as a thank you for their involvement. For the second stage of the research, young people were provided with a £5 high street voucher. These reimbursements were deemed appropriate and substantial enough for the population of young people involved in the research.

3.10 Summary

To summarise, the current research programme has adopted a pragmatic epistemology and a mixed, exploratory sequential design whereby the phases of research were fixed before they commenced. A systematic literature review, photo elicitation interview and thematic analysis, and finally questionnaires, hair samples and statistical analysis were combined with two points of interface. Steps were taken to address the challenges of research with young people and young carers whilst ethical considerations surrounding this population were made.

Chapter four: Coping and Adjustment in informal carers; a systematic review

4.1 Chapter overview

This chapter provides a detailed account of the process undertaken to conduct a systematic review surrounding informal carer adjustment and coping. PRISMA guidelines were followed to ensure rigour and quality. A rationale for the systematic review is given, alongside a detailed method and search strategy section. Findings of the study were categorised into themes, which are presented in the results section. These findings are then discussed, alongside methodological issues, strengths and limitations of both the systematic review literature, and the systematic review itself, as well as suggestions for future research.

4.2 Contributions to this chapter

This study has been published in Health Psychology Open. The reference for the manuscript is Hawken, T., Turner-Cobb, J.M., & Barnett, J. (2018). Coping and Adjustment in caregivers: A systematic review. *Health Psychology Open*, 1-10, 5, (2).

The majority of the current chapter is taken directly from the manuscript. The student, Tamsyn Hawken (TH) and Professor Julie Turner-Cobb (JTC) developed the research question, protocol for the study and discussed inclusion and exclusion criteria during the screening process. The manuscript was written by TH, with guidance and editing from JTC and Professor Julie Barnett (JB). TH responded to reviewer comments and carried out revisions on the manuscript during the submission process with guidance from JTC and JB. TH is the lead author on the manuscript. The full, published manuscript can be found in Appendix A.

4.3 Introduction

As established in the general literature review outcomes in informal carers vary, and not all outcomes are detrimental. Resilience may facilitate effective coping in carers and many demonstrate positive adjustment to their situations.

In the current review, coping is considered a process leading to adjustment, where adjustment encompasses the psychophysiological outcomes of coping; positive adjustment is defined as adaptive response to a challenge, across physical, interpersonal, cognitive, emotional and behavioural domains (Larsen & Lubkin, 2009). Thus those that positively adjust demonstrate resilience, the abiliy to recover from stressful life events or challenges with either the same level or an increased level of resources. The term adjustment was used in this review as an informal literature review showed that few carer studies explicitly used the term resilience in their research to capture outcomes or pathways within carer populations. Therefore, 'adjustment' encapsulated a number of terms that relate to outcomes in the caregiving context, and is most often used in this particular field.

Many studies offer theoretical explanations of carer outcomes based on the Transactional model of Stress and Coping (Lazarus & Folkman, 1984) where coping responses are inherent within the process of meeting demands and challenges. Typically coping responses are categorized as problem-focussed, emotion-focussed or cognitive. The impact of coping responses has been studied in carers, and has found that appraisal and coping responses were significant predictors of outcomes in adult dementia carers (Haley et al., 1987). This has been further demonstrated where caregiving factors, cognitive appraisal, coping strategies and coping resources were predictors of adjustment in adult MS carers (Pakenham, 2001).

Use of problem-focussed coping is associated with better carer adjustment than emotion-focussed coping (Pakenham, 2001) and adverse caregiving effects in adults can be lessened with adequate social support and problem-focussed coping (Branscum, 2010). Yet defining psychological concepts such as coping and adjustment is challenging in any population and the transactional model has been criticised for its oversimplification and disregard of the situational nature of coping (Schwarzer & Schwarzer, 1996). Others have incorporated multi-dimensional approaches and highlight the effectiveness of strategies may vary depending on the situation and stressor encountered (Carver et al., 1989). Similarly, Skinner (2007) proposed twelve 'families' of coping based on function and contribution to adaptation. At a physiological level, the concepts of allostasis and allostatic load are a well-accepted explanation for adjustment in underlying mechanisms resulting in differential health outcomes (McEwen, 1998; Sterling & Eyer, 1988). These concepts have been applied to a model of adjustment in investigating the physical impact of caregiving (Vedhara et al., 1999; Vedhara et al., 2002).

Whilst empirical studies have considered factors associated with adjustment and coping in the caregiving population, reviews conducted in this area predominantly describe or collate findings assessing the needs of carers, providing data on prevalence and impact. Furthermore, reviews are limited in that they focus primarily on problem and emotion focussed or cognitive coping strategies, rather than exploring further factors, or coping resources (such as professional support or social support) directly in relation to psychological and physiological adjustment or resilience in a carer population.

The literature has not been systematically reviewed to draw conclusions about the factors associated with coping behaviours which may contribute to overall resilience. Reviews that have considered coping and adjustment in carers are now outdated (Low, Payne, & Roderick, 1999) or focus on specific caregiving populations (e.g. stroke carers, del-Pino-Casado et al., 2011).

4.3.1 Study aims

The aim of this study was to assess coping and adjustment across all informal carer ages and conditions cared for, using a systematic review. Identifying coping factors associated with adjustment or stress resilience can inform future research and health providers aiming to support

carers. A secondary aim of this study, within the context of this programme of research, was to determine the extent to which young carer research is a feature within the overall informal carer literature, and to establish a foundation upon which to base the further studies within this research.

4.4 Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; see appendix B) guidelines and checklikst were used (Moher, Liberati, Tetzlaff & Altman, 2010).

4.4.1 Search strategy

Four online databases (PsychNET, Web of Science, Pubmed and Scopus) were searched. References of retrieved papers, previous reviews and books were scanned. Three experts in the area were consulted via email where appropriate. A search of cited reference lists was also carried out. Figure 4.1 below details the search process.

Searches were conducted (05/11/2015, repeated 09/10/2017 and 07/01/2018) using key words (coping, adjustment, outcomes and caregivers/carers) and Boolean operators. Some search terms differed between databases due to the availability of index terms and database specific filters (e.g. PsycNet search: Coping behaviour AND Adjustment OR Outcomes AND caregiv* NOT intervention. Web of Science search: Coping AND Adjustment OR Outcomes AND "Family caregivers" NOT intervention*). There were no publication date limits. Both quantitative and qualitative studies were reviewed.

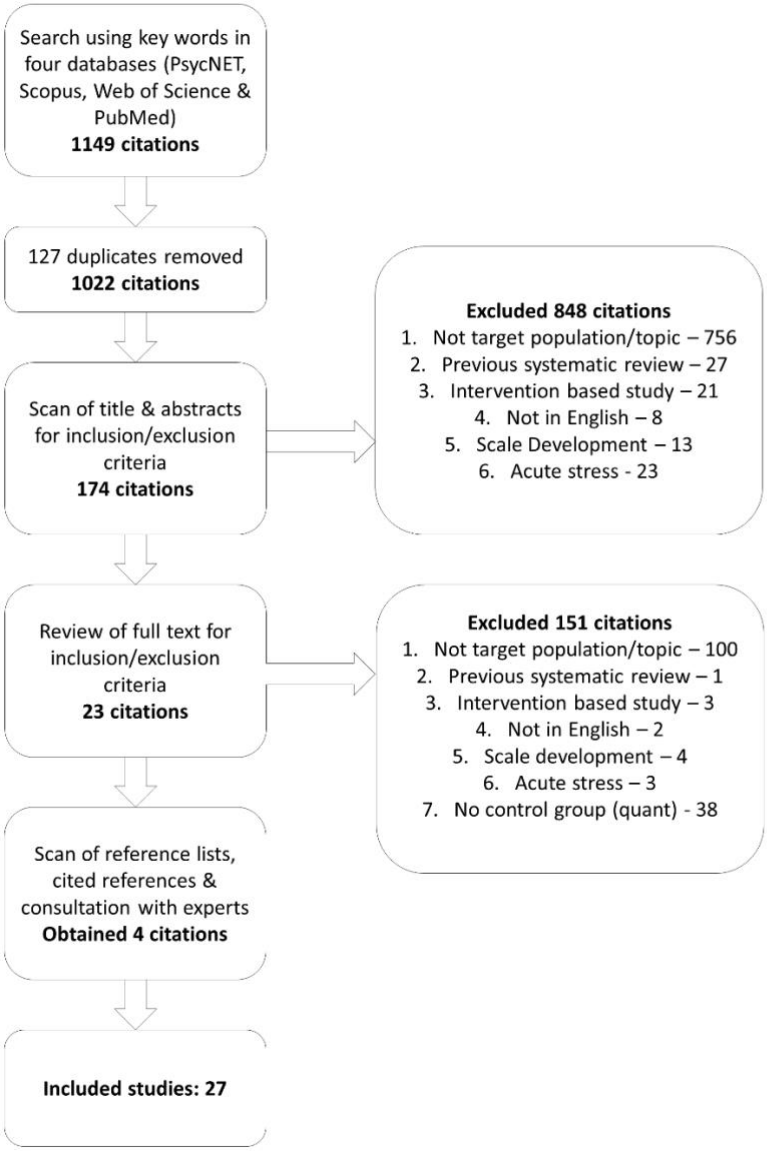

Figure 4.1 Systematic review search process as per PRISMA guidelines

4.4.2 Study selection

Duplicates were removed and results were reviewed based on titles and abstracts. Full texts were retrieved for eligible studies and further reviewed for inclusion and exclusion criteria. Data were extracted from articles using a piloted data extraction form that included information about aims, design, sample, measures and findings.

4.4.3 Inclusion and exclusion criteria

Inclusion criteria for quantitative studies were that they: (1) reported experiences of informal carers, (2) investigated chronic stress, (3) measured coping and/or outcomes; and (4) included a control or comparison group. Inclusion criteria for qualitative studies were that they: (1) reported the experiences of informal carers, (2) investigated chronic stress; and (3) discussed

coping styles/strategies and outcomes. A control or comparison group was required for quantitative studies to reflect methodological quality, but was not required for qualitative studies.

Studies were therefore excluded if they: (1) were not the target population or topic (e.g. animal studies, formal carers or did not investigate coping), (2) were a previous systematic review, (3) were an intervention based study, (4) were not written in English and a translation was not available, (5) were a scale development study, (6) investigated acute stress or (7) did not have a control group (for quantitative studies).

Two reviewers assessed articles against criteria; checking and confirmation was conducted by the second reviewer and discrepancies were resolved through discussion.

4.4.4 Quality ratings

All selected studies were subjected to quality appraisal. Quantitative studies were rated for quality across four dimensions; sample; attrition; measurement; and analysis using 11 criteria developed by Laisné, Lecomte, and Corbière (2012). Studies were rated zero (no; partial) and one (yes), therefore the maximum score was 11. All studies reached moderate (>5) to high quality (>8); none were excluded.

Qualitative studies were rated using Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet, Lee, & Cook, 2004). Ten criteria were used to assess design, sampling, data collection and analysis and were rated zero (no), one (partial) and two (yes); maximum score was 20. All qualitative studies were rated as high (>15).

4.5 Results

A total of 27 empirical papers met inclusion criteria; 13 used a quantitative and 14 used a qualitative methodology (see appendix C for full study details). Publication years ranged from 1996 to 2015. All quantitative studies used self-report measures to collect data and were predominantly cross-sectional. One study was longitudinal (with a control group). All of the quantitative studies used a between-groups design (e.g. carer vs non-carer, dementia carer vs stroke carer). Controls and comparison groups comprised of non-carers, carers of healthy individuals, or carers of a comparison health condition. Qualitative data in all 14 studies were collected via semi-structured interview, with one study also using photo elicitation and another using observation. Qualitative analysis was mostly thematic, alongside interpretive phenomenological analysis, content analysis and grounded theory. One qualitative study was longitudinal and presented as a case study.

A total of 2084 participants were included, with a minimum of one participant and a maximum of 246. The minimum mean age was 17 years; maximum 74 years. Care provided

was in the context of a range of health conditions as indicated in Table 4.1 and carers were related to care recipients as grandparents, spouses, parents and offspring.

Table 4.1

Health conditions and contexts of individuals cared for by carers

Health condition or context
Alzheimer's disease /Dementia
Attention Deficit Hyperactivity Disorder
Autism Spectrum Condition (ASC)
Closed/Traumatic Brain Injury
Human immunodeficiency virus
Intellectual disability
Lung transplant candidates
Mental Illness
Multiple Sclerosis
Pulmonary heart disease
Spinal Cord Injury
Stroke

Findings from the 27 papers were synthesised using thematic analysis (Braun & Clarke, 2006). Substantive insights were identified in four areas: 1) problem versus emotion-focussed coping; 2) use of cognitive strategies; 3) factors associated with psychological adjustment; and 4) factors associated with physiological adjustment. There were also clear methodological issues.

4.5.1 Use of problem versus emotion-focussed coping

The studies in this review identified a number of coping strategies utilised by participants, categorised as problem or emotion-focussed coping, in line with the definitions presented earlier.

Carers reported using fewer positive strategies and relied less on problem-focussed coping than non-carers (Mausbach et al., 2013; Pakenham & Bursnall, 2006). Some studies investigated the relationship between coping styles and adjustment. Mausbach et al. (2013) identified that carers using fewer positive strategies (e.g. engaging in pleasant activities, seeking

social support) and greater negative coping strategies (e.g. self-blame, avoidance), reported poorer psychosocial outcomes and adjustment compared to non-carers. Negative impacts included increased depressive symptoms, negative affect, fear, hostility and sadness.

Problem-focussed coping was generally considered most adaptive and associated with less psychological distress and more positive outcomes (Bachanas et al., 2001; Pakenham & Bursnall, 2006). Ten studies reported examples of problem-focussed strategies adopted by carers. Some of these strategies were actions the carer took to reduce their burden, (reducing work hours, using paid carers, accepting financial hardship, integrating care into family culture, daily routines, incorporating risk management into daily life, utilising social support and effectively planning activities and care; Dickson et al., 2012; Kita & Ito, 2013; McCausland Kurz & Cavanaugh, 2001; Sun, 2014; Williams et al., 2014). Other problem-focussed coping involved action or changes in behaviour surrounding the care recipient to reduce time and labour (e.g. coping with their physical limitations, engaging them in activities, lowering expectations of them, avoiding confrontation, finding humour, overseeing health and treatments and modifying communication methods). Finally, problem-focussed strategies included communicating with others and researching the health condition to increase a sense of control (Williams et al., 2014). Carers reported comparing their relative's health through books and social media: communicating with schools and others in similar situations through online platforms or support groups and researching online about the cared for person's condition (Le Dorze, Tremblay, & Croteau, 2009; McCausland Kurz & Cavanaugh, 2001; Sun, 2014; Williams et al., 2014). Although problem-focussed strategies were generally reported as most helpful and associated with more positive outcomes in carers, in many cases these were not used more than emotion-focussed strategies.

Overall, studies that reported use of emotion-focussed coping strategies found associations with negative outcomes, with carers less able to regulate their negative emotions compared to controls (Ruiz-Robledillo & Moya-Albiol, 2013). Figueiredo and colleagues (2014) found that greater use of emotional coping was associated with poorer mental health perception. Sander, High, Hannay, and Sherer (1997) report associations between greater use of emotion-focussed coping and levels of psychological and emotional distress. Others specify emotion-focussed techniques such as distraction and avoidance as being considered unhelpful by carers. Haley and colleagues (1996) reported that high levels of avoidance coping and low levels of approach coping were associated with greater depression and decreased life satisfaction. Wishful thinking and denial, were also found to be related to greater psychological distress (Pakenham & Bursnall, 2006). Despite the generally reported negative impact of emotion-focussed coping, there were some exceptions where carers felt these strategies were helpful, including venting emotion, taking time out, and having a 'good cry' to release emotional energy (Azman, Jamir Singh, & Sulaiman, 2017; Dickson et al., 2012; Figueiredo et al., 2014).

The quantitative longitudinal study examined use of problem and emotion-focussed coping in mothers caring for an adult child with an intellectual disability or mental health condition (Kim et al., 2003). Higher initial and increased use of problem-focussed coping predicted declining levels of burden and depressive symptoms. More use of emotion-focussed strategies increased burden and depressive symptoms and contributed to poorer parent-child relations.

Finally, three papers reported the use of religious coping, whereby carers described a strong faith or spirituality enabling them to cope with their caregiving responsibilities; having strong religious convictions enabled better stress management (Azman et al., 2017). Church services were a source of social support and seeking advice from a pastor was also valued (Gerdner, Tripp-Reimer, & Simpson, 2007). Attending church services and upholding religious practices and values allowed carers to maintain a life separate from caregiving, which they considered important (Thornton & Hopp, 2011).

4.5.2 Use of cognitive strategies

Cognitive coping strategies were identified in six papers. These strategies involved a conscious effort to alter perceptions, appraisals or cognitions surrounding caregiving to promote a greater sense of well-being. Unlike problem or emotion-focussed coping, cognitive strategies are not behavioural and are defined as thoughts used to deal with stressful or challenging situations which typically involve the mental perception an individual has surrounding their ability to manage a stressor (Lazarus & Folkman, 1984). Most reported was the use of acceptance. This involved acceptance of inequalities surrounding caregiving and the individual being caring for, as well as accepting that the situation was unchangeable and that life could never be the same again (Azman et al., 2017; Dickson et al., 2012; McCausland Kurz & Cavanaugh, 2001; Williams et al., 2014; Zegwaard, Aartsen, Grypdonck, & Cuijpers, 2013). Appraisal was highlighted as an important factor. Haley et al. (1996) found that the effects of stressors were mediated by the appraisal carers had of their experiences, and Pakenham and Bursnall (2006) reported that higher stress appraisals were related to higher distress and lower life satisfaction in carers.

Social comparisons were also used by carers, including comparing their current situation to another difficult situation in their past, such as the illness or death of parents (McCausland Kurz & Cavanaugh, 2001). Additionally, carers reported making downward comparisons to others in similar circumstances, as well as considering themselves more fortunate and comparing their resources to others to feel efficient and capable (Williams et al., 2014).

Some cognitive strategies involved perceptions of the carer role and carers reported that valuing their role, retaining autonomy, identifying benefits and finding meaning in their experiences, helped them adjust to their situation (Kitter & Sharman, 2015; Thornton & Hopp,

2011; Zegwaard et al., 2013). Reframing aspects of their experience enabled effective coping and involved looking on the bright side; finding humour when feeling helpless and reframing perceptions positively (Bailey, Letiecq, Erickson, & Koltz, 2013; Williams et al., 2014). In particular, taking a gain rather than a loss mentality was deemed helpful by those who chose to perceive their caregiving as a choice and voluntary act of compassion, rather than a forced obligation (Zegwaard et al., 2013).

4.5.3 Factors associated with psychological adjustment

Social support was frequently correlated with positive psychological adjustment. High levels of social support correlated with higher positive outcomes, less distress and better health in carers (Haley et al., 1996; Pakenham & Bursnall, 2006). Wong et al. (2015) found that a strong, positive marital bond, affection and feeling cared for were supportive of good adjustment in carers. Consistent positive social interaction which enabled individuals to feel supported in terms of their emotions and self-esteem was also deemed important for adjustment and promoted resilience (Kaplan, 2010; McCausland Kurz & Cavanaugh, 2001; Ruiz-Robledillo et al., 2014). Specifically, carers noted that opportunities to share information and their experiences within their social network positively influenced their adjustment and outcomes (Kita & Ito, 2013; McCausland Kurz & Cavanaugh, 2001). Social support also took the form of practical support and was associated with adjustment (McCausland Kurz & Cavanaugh, 2001). Practical support in the form of physical care often came from friends or family members, such as adult children (Gerdner et al., 2007; Kaplan, 2010). Tangible support was also sought in a more formal manner from professional services such as adult day care or home health services, and was positively associated with adjustment (Gerdner et al., 2007).

Factors associated with poorer adjustment were identified in two studies. Bachanas et al (2001) found a greater number of daily hassles, use of emotion-focussed coping and fewer family resources, were related to poorer adjustment. Pakenham and Bursnall (2006) established that lower levels of perceived choice in caregiving were associated with lower adjustment on measures such as life satisfaction, benefit finding and positive affect.

4.5.4 Factors associated with physiological adjustment

Only six studies reported findings regarding physiological adjustment, five of which measured self-reported physical health to determine health status. Two studies found that carers endorsed more symptoms using physical health measures and worse health than controls (Mccallum, Longmire, & Knight, 2003; Ruiz-Robledillo & Moya-Albiol, 2013). Some studies reported specific factors positively associated with better self-reported health in carers and these included increased use of problem-solving coping and higher resilience (Figueiredo et al., 2014; Ruiz-Robledillo et al., 2014). Other studies reported factors that were negatively associated with self-reported health. Ruiz-Robledillo and Moya-Albiol (2013) found that higher trait anxiety,

greater cognitive-oriented problem coping and higher levels of burden were associated with poorer health in carers. However, Kim and Knight (2008) found that coping was not associated with the impact of caregiving upon health outcomes.

In addition to self-report measures, four papers used biomarkers of stress in the form of blood pressure and salivary cortisol. Studies assessing cortisol have generally found support for caregiving as a stressor associated with increases in cortisol levels and disruption of the diurnal decrease or awakening response. Higher cortisol and blood pressure were reported in carers compared to non-carers (Kim & Knight, 2008; Ruiz-Robledillo & Moya-Albiol, 2013). Kim and Knight (2008) reported that lower instrumental social support was associated with higher levels of salivary cortisol, and Ruiz-Robledillo et al. (2014) found that resilience was negatively correlated with carers' cortisol awakening response (CAR) and also reported lower total salivary cortisol concentration, as assessed by a smaller area under the curve, over the sampling period. However, Merritt and McCallum (2013) found that greater use of positive religious coping correlated with a flatter cortisol decline across the day for African-American carers coping with behavioural problems in family members with dementia compared to non-carers, suggesting that African-American carers require a wider range of religious coping skills that incorporates both positive and negative religious coping.

4.5.5 Methodological considerations

In this systematic review, a number of methodological issues were evident. Since evidence shows that caregiving can significantly impact the psychosocial and physical health of individuals, it was surprising that 23 papers assessed only psychosocial factors; most particularly, coping strategies, coping resources, social adjustment, stress appraisal and positive and negative affect. Only four studies utilised physiological measures, notably blood pressure and salivary cortisol. Eight studies used self-reported physical health and symptom inventory checklists. Reviews of method sections found a wide variety of measures were employed, approximately 60 different scales and measures. Of these, eight were carer specific.

Although 15 studies referred to theory, 12 did not. Of the 13 quantitative studies, nine referred to theory, most commonly the transactional model of stress and coping (Lazarus & Folkman, 1984) and the Sociocultural Stress and Coping Model for Caregivers (Aranda & Knight, 1997). In some instances these theories guided research and were tested, but in others were provided to explain findings. Of the 14 qualitative studies, six referenced theory, most often the ABCX Model of Family Adaptation (McCubbin & Patterson, 1983) and Stress Coping Frameworks (Knight, Silverstein, McCallum, & Fox, 2000; Lazarus & Folkman, 1984).

Only two of the 27 studies were longitudinal. The first, a quantitative study (Kim et al., 2003) provided predictive data regarding problem and emotion-focussed coping in mothers caring for an adult child. The second, a seven-month qualitative case study (Le Dorze et al., 2009) observed adjustment of a daughter whose father had aphasia and had suffered a stroke.

Finally, much of the informal carer literature has focussed on older adults, with some investigating younger adults, very few explore coping and adjustment in young carers (<18 years old). Of the 27 studies, 23 reported the mean age of the carers; in 22 of these studies it ranged from 25 to 74 years. Only one study reported a mean carer age that could be considered a young carer population; ages ranged from 10-25 years (mean age 17 years).

4.6 Discussion

Through the systematic review of quantitative and qualitative literature, a number of coping factors and resources associated with adjustment in informal carers were identified.

4.6.1 Summary of findings

Problem-focussed coping as a method for adjusting to the role and responsibilities of caregiving was associated with more positive adjustment and outcomes. Emotion-focussed coping was associated negatively with carer adjustment and linked to increased psychological and emotional distress. Despite this general finding, some subjective reports in qualitative data identified helpful emotion-focussed techniques. This highlights the dynamic and changing nature of coping, and the importance of taking into account individual circumstances. Previous research has found that strategies cannot necessarily be categorised into positive or negative approaches, and that some stressors, such as those that cannot be changed by way of problem-focussed approaches, benefit most from emotion-focussed techniques (Lazarus & Folkman, 1984). Unfortunately, the literature in this review does not offer information regarding the fit between the stressor and a chosen coping strategy in carers. This warrants investigation.

In addition to problem and emotion-focussed strategies a number of cognitive strategies were identified. Whilst cognitive factors can be viewed as independent of problem and emotion-focussed coping, it is important to acknowledge that the three strategy styles cannot always be viewed separately. The associations between different coping styles identified in this review support the findings of previous research demonstrating that a combination of problem-focussed, emotion-focussed and cognitive strategies is often the most effective way to cope with stressors (Pakenham, 2001). The studies in this review do not provide insight regarding the balance between coping approaches or the number of unique strategies employed.

Ten papers in the review identified factors associated with poor adjustment (three studies) and positive adjustment (seven studies). The factor most frequently positively correlated with adjustment was emotional and tangible social support. Carers highlighted that sharing their experiences and information with other carers was useful, confirming the protective nature of social support against social judgement and perceived stress (Beck, 2007).

Although only six of the papers reported physiological adjustment in carers, some common findings were identified. Overall this review supports previous findings that caregiving is associated with elevated cortisol levels and subjective reports of poorer health compared to

non-carers. Since the immune system naturally deteriorates with age (termed immunosenescence), the impact of stress may be greater or more pronounced in older individuals (Vedhara et al., 2002). Findings from adult and elderly carers may not represent young carers, who potentially have a more optimum immune system. The mean age of participants in the six studies reporting physical health outcomes was 55.5 years. The informal carer literature would benefit from further research surrounding physiological outcomes across all age groups to adequately disaggregate the physiological effects on immune functioning by age. It is evident from this review that it is important to extend research using physiological markers, such as salivary cortisol, to young carers. This has not yet been conducted and could provide an indication of the effects of caregiving across the lifespan. This is supported by Barnett and Parker's (1998) assertion that although a great deal of research has been conducted with adult carers, the same cannot be said for young carers. In particular, Simon and Slatcher (2011) note that little is known about the physical health of child carers compared to adults. This review highlights this limitation.

4.6.2 Methodological considerations and limitations of the review literature

Numerous methodological considerations regarding the studies in this review were identified. During data extraction it was evident that a variety of quantitative measures were employed to assess aspects of caregiving; there were very few designed specifically for carers. An important question to address is whether tailor-made measures for carers would be useful to assess factors such as burden and stress in this unique population. Furthermore, a more consistent use of measures across studies would increase their comparative value and enable meta-analyses to be conducted.

Regarding outcome measures, only six studies took a biopsychosocial approach, measuring physical health through either self-report or physiological measurement. The remaining 21 studies measured purely psychosocial factors and did not consider physical outcomes. Assessment of physiological outcomes in the adjustment of carers however, is gaining interest, as shown by the more recent studies reviewed; we would call for such assessments receiving greater attention.

There is limited focus on young carers, with only one study investigating this population. The most recent UK census reported 177,918 young carers between five and 17 years old, however this is believed to be a gross underrepresentation. Though research has identified the potential negative impact of early caregiving (Thomas et al., 2003) not all young carers or children living with ill parents demonstrate these outcomes. In fact, some show evidence of resilience, particularly physiologically (Turner-Cobb et al., 1998). It is imperative that future research investigates this population to determine resilience factors. The transactional model (Lazarus & Folkman, 1984) which many studies refer to, describes a dynamic process, capable of changing and developing over time. Exposure to caregiving at a

young age may impact adulthood and longitudinal study of carers at various points in their life would allow the process of coping to be observed over time and investigation of the temporal demands of caregiving.

A call for greater longitudinal research in carer coping is further supported by the majority of quantitative studies in this review being of cross-sectional design and offering little predictive value to assess the direct impact of specific coping strategies on adjustment. Whilst cross-sectional studies have provided insight in this relatively new field, progression towards longitudinal assessment with the power to predict the effect of coping strategies upon adjustment is needed.

4.6.3 Strengths of the review literature

Despite the numerous limitations noted within the papers there are strengths. Firstly, all studies, when subjected to quality appraisal were deemed sufficient in quality to be included in the study, suggesting research in this area is being conducted rigorously. Secondly, although some studies reported the negative impact of caregiving and factors associated with poor adjustment, many studies took a resiliency approach, focusing on coping factors positively associated with adjustment. Future development of interventions designed to help carers cope effectively can be enhanced by inclusion of such factors.

4.6.4 Limitations of the review

This systematic review has limitations. Firstly, due to language barriers, papers not written in English were excluded. Despite this, the included studies were carried out in a range of countries, including the UK, USA, Portugal and Korea (Bachanas et al., 2001; Barbosa, Figueiredo, Sousa, & Demain, 2011; Dickson et al., 2012; Kim & Knight, 2008) reducing the likelihood of cultural bias. Secondly, only published papers were included, this was to ensure a level of quality subject to peer-review. It is possible that we introduced a bias by not representing studies with unexpected or non-significant findings. However, the inclusion of qualitative literature, with sufficient quality ratings, that do not require statistical analysis or significance ensures a variety of findings were reported. Furthermore, this review used the terms ‘carer’ and ‘caregiver’ when searching, which poses a possible issue as these terms are relatively new in the literature. Early work used descriptive terms (e.g. spouses of individuals with an illness or children living with parental illness) rather than identifying individuals as carers per se (Folkman, Moskowitz, Ozer, & Park, 1997; Westbom, 1992). It is possible that use of these terms resulted in the exclusion of relevant literature. Finally, though the term adjustment was chosen for use in this review due to its encompassing nature with regard to outcomes and coping, it is possible that not deconstructing this term and focusing on specific aspects of adjustment or resilience may also have limited the literature found when searching.

4.6.5 Chapter summary

This study reviewed the literature surrounding coping and adjustment in informal carers across all ages, to identify outcomes associated with caregiving and to contribute to this developing area of research by identifying coping factors associated with adjustment.

This review found that problem-focussed coping is associated with more positive adjustment than emotion-focussed coping. Cognitive strategies (e.g. acceptance, appraisal) were positively related to adjustment, as well as social support, particularly with regard to physiological outcomes. Given these findings, those seeking to provide carers with support may consider harnessing these factors, for example, developing coping skills and social support networks.

Methodological issues were identified which highlight considerable gaps within the literature and present a strong call for research that seeks to (1) address the imbalance between studies using purely psychosocial measures and the few using physiological measures to develop a deeper understanding regarding the physiological impact of caregiving, (2) develop longitudinal studies to provide predictive data and (3) investigate young carers to assess the impact of caregiving across the lifespan. Beyond this review, further meta-analytic examination of findings in this field is warranted and called for.

To develop appropriate interventions for a growing informal carer population, a clear and coherent understanding of the mechanisms underlying coping, adjustment, vulnerability and resilience in operation is needed. This systematic review highlights the importance of such work and draws attention to the gaps in carer research across different age groups, as well as the need for a more coherent understanding of consistencies and discrepancies in carer outcomes at different points across the lifespan.

Chapter five. Through the eyes of a young carer: A photo elicitation study

5.1 Chapter overview

This chapter summarises the findings of a qualitative study using a photo elicitation method to explore potential protective resilience factors in a young carer population, in line with the socioecological framework proposed by Windle and Bennett (2011) which categorises protective factors into individual, community and society, where society includes the surrounding environment. Background is provided and the method is described. Themes identified are presented with supporting quotes direct from interviews and photos taken by young carers where appropriate. Findings are then discussed in relation to the previous literature and socioecological framework of resilience.

5.2 Introduction

For approximately five decades, researchers have explored resilience in young people and children in the context of stress (Southwick et al., 2014). Resilience is predominantly defined by theorists as the result of an interaction between an individual experiencing stress, internal factors and external environmental factors. Factors that promote positive adjustment and outcomes, are considered protective factors, providing a buffer between risk factors, stress, and negative or poor adjustment outcomes (Rutter, 1979).

Given that caregiving can negatively impact biopsychosocial health and well-being, as established in both the literature and systematic review (chapters two and four respectively), the role of an informal carer can be conceptualised within a resilience framework as a risk factor. With this in mind, Windle and Bennet (2011) proposed a socioecological framework of resilience for carers, categorising protective factors at individual, community and society levels. Doing so enables a distinction between different sources of resilience and this framework has been used to explore factors that facilitate and hinder resilience in older carers providing care for a spouse with dementia (Donellan, Bennett and Soulsby, 2015). Factors were identified at all levels of the model and included psychological assets, material resources, family relations, social participation, health and social care, and other services. This study took a resilience perspective, focussing on strengths rather than pathology in adult and elderly carers (Slatcher et al., 2015), but the systematic review conducted in this research programme identified that only one study has used a resilience approach with young carers (Pakenham & Bursnall, 2006). This is despite influential theorists such as Werner (1989) arguing, over 30 years ago, that even when growing up in challenging and stressful situations, such as living with parental illness, children can show remarkable resilience. Indeed, despite the detrimental impacts of caregiving at a young age such as increased negative emotion (Dearden & Becker, 2002; Sahoo & Suar, 2010), increased risk for mental health issues (Cree, 2003) and social restrictions (Earley et al., 2007; Hamilton & Adamson, 2013; Lloyd, 2013; Rose & Cohen, 2010; Thomas et al., 2003) many

young carers also report benefits and positive outcomes indicative of resilience. These include feelings of gratification, satisfaction, pride and confidence (Becker, 1995; Rose & Cohen, 2010) in addition to earlier and increased development of maturity, responsibility and life skills such as tolerance, independence, helpfulness, endurance and sympathy (Ireland & Pakenham, 2010; Lloyd, 2013; Rose & Cohen, 2010; Thomas et al., 2003). Though there are clear negative consequences associated with caregiving at any age, there are carers who positively adapt to the chronic stressor of caregiving, which is potentially an indicator of resilience within this population and warrants a resilience perspective to be taken to explore the protective factors that may enable young carers to positively adapt to their circumstances and caregiving responsibilities.

Luthar, Cicchetti and Becker (2000) have criticised resilience research for lacking context. They advocate for more qualitative research which can enable relevance, arguing that researchers have a duty to account for the voices of young children to understand their circumstances and lived experiences, rather than depending on the views of third parties (such as parents or teachers) and assuming they can offer more insight than the young person themselves. Yet over a decade and a half after these assertions, it has been highlighted that "the voices of young people remain somewhat absent in resilience research" (Shean, 2015, pg31), and this is particularly the case with a population of young people who are carers. Hence, this study adopts a qualitative research design utilising a photo-elicitation interview method, taking a resiliency perspective to identify potential protective factors in young carers.

5.2.1 Contextualising this study within the wider research programme

The current study builds upon the findings of the systematic review to extend knowledge of potential protective factors in a caregiving population which may contribute to coping, adjustment and resilience. In particular, this study explores whether the factors identified in the systematic review, and predominantly in adult and elderly carer populations, are relevant or present in a group of young carers, enabling confirmation of previously identified factors, but also allowing opportunity for further factors, specific to young carers, to be explored.

As the second study in a three phase programme of research, this qualitative interview study also seeks to provide a basis upon which to select variables to measure in the third phase of this research, a quantitative study. This study therefore builds upon the systematic review, and provides context and guidance for quantitative study with young carers.

5.2.2 Study aims

Given the lack of resilience research surrounding young carers, but evidence showing that young carers can adapt and cope with their circumstances, there is a need to explore potential protective factors in young carers, to identify possible pathways to resilience,

particularly due to the increasing prevalence of this population. Furthermore, there is a need to capture the context of caregiving and ensure young people can voice their experiences.

Therefore, this study aimed to qualitatively explore protective resilience factors in young carers using the socioecological framework proposed by Windle and Bennett (2011) as described in the literature review (chapter 2; 2.4.4) and the novel method of photo-elicitation.

5.3 Method

5.3.1 Participants and recruitment

Twelve children and adolescents (9 female) between the ages of 5 and 18 years, providing care to a family member were recruited via opportunity and volunteer sampling following institutional ethical approval. Exclusion criteria included those with special educational needs due to the requirement to successfully engage with cameras and instructions.

Participants were recruited via carers' centre events, advertisement within carers' centres or contact with carers' centre staff across three organisations. Sources of recruitment are displayed in table 5.1 below, alongside demographic and contextual information for individual participants.

Table 5.

Demographics, contextual information and recruitment source for each participant

Name (Gender)	Age	Living situation	Family member cared for (age)	Condition cared for	Recruited via
Samantha (F)	14	Mother, brother & visiting step-dad and step-sister	Brother (11) Step-sister (16)	Epilepsy and RETS syndrome Autism	Carers' centre 1 (support worker)
Bella (F)	14	Mother & brother	Brother (11)	Asperger's syndrome	Carers' Centre 2 (support worker)
India (F)	18	Mother & two brothers	Brother (19) Mother	Non-verbal Autism Mental health and physical ailments	Young Carer event (run by Carers' Centre 3)
Sophia (F)	14	Mother, brother & sister (Penny)	Mother Sister (9)	Fibromyalgia/Coeliac Disease Chronic pain	Carers' Centre 1 (support worker)
Penny (F)	9	Mother, brother & sister (Sophia)	Mother	Fibromyalgia/Coeliac	Carers' Centre 1 (support worker)
Tobias (M)	8	Mother & brother	Mother Brother (4)	Back pain No condition – general help	Carers' Centre 2 (poster)
Charlie (M)	10	Mother, father & brother	Brother (12)	Cerebral Palsy, Brain damage, severe learning delay, Eczema	Carers' Centre 2 (poster)
Olivia (F)	9	Mother & brother	Mother	Chronic pain and mobility issues	Carers' Centre 2 (poster)
Arthur (M)	9	Mother, father & brother	Brother (7)	Anger issues and suspected ADHD	Carers' Centre 2 (support worker)
Krissy (F)	17	Mother & sister (24)	Mother	Multiple Sclerosis	Carers' Centre 2 (poster)
Rosie (F)	5	Mother, father, sister (Beth) & brother	Brother (10)	Autism	Carers' Centre 2 (support worker)
Beth (F)	7	Mother, father, sister (Rosie) & brother	Brother (10)	Autism	Carers' Centre 2 (support worker)

Note. M = Male, F = Female, Name = a pseudonym, Age= years

5.3.2 Design

Using a qualitative strategy and a cross sectional design, in person interviews were conducted with young carers. An auto-driven photo elicitation method was used, which involved participants taking photos (as opposed to researcher provided photos) based on a number of prompts and the researcher introducing these photos as objects of discussion during interview (Clark, 1999). The choice of prompts in photo elicitation must be tailored to the research question and the target population (Cappello, 2005). For this study prompts were drawn from the general resilience and carer literature.

5.3.2.1 Photo Elicitation Interview

Mauthner (1997) encourages a child centred approach and using photos allows the researcher to "invoke comments, memory, and discussion in the course of a semi-structured interview" (Banks et al., 2001, pg87). The object of the research becomes the photos rather than the participants, promoting autonomy, competence and resilience (Carter et al., 2015). Jorgenson and Sullivan (2009) describe photo elicitation as enjoyable, allowing children to engage as active research participants enabling them to portray specific moments in their lives that might be overlooked in traditional interviews. Furthermore, photo-elicitation with children has potential to address the power imbalance that can exist within research and encourage a comfortable, safe and open atmosphere for discussion and disclosure (Mandleco, 2013). This method has been used with young people to explore preparations for school (Miller, 2016), negative interactions between early adolescents (Pabian et al., 2018) and childhood grief (Stutey et al., 2016). To our knowledge this is the first time the method has been used with young carers.

5.3.3 Materials

Young carers were given a 27-exposure disposable camera (Fujifilm 'Quick Snap' with flash) with a cover which included labels of key features (exposure count, flash and viewfinder) and 14 prompts. The cover was based upon a design used in a previous photo elicitation study with informal carers (Long et al, 2017). Prompts were developed for young carers to take photos of their caring experience and how they manage it (i.e. please take a picture of: 'something that makes you sad'; 'something hard about being a carer' (full list of prompts and camera cover can be found in Appendices D and E). Participants could take more than one photo per prompt or take photos unrelated to the prompts if they illustrated their carer experience and the provided prompts had been addressed. Young carers were given a booklet with instructions for taking photos and space to record notes and dates, such as upcoming camera collection or interview time.

Once developed, photos were discussed as part of a semi-structured interview, therefore the photo's themselves were not analysed, but the transcripts of the interviews formed the data used in analysis. The interview schedule included introductory questions to develop rapport and

gather demographic information and context surrounding the participants' caregiving. The main interview questions were designed to elicit responses through discussion of each photo and explored the stories attached to photos, thoughts and feelings from when the photo was taken and upon seeing the developed photo, and finally asked the young carer how they coped with the situation they had photographed. The interview schedule (see appendix F) was designed based on limited carer resilience literature and was piloted with two young carers. One amendment was made after feedback from a young carer to the question surrounding caregiving context, whereby the question 'can you tell me about the person you care for?' was changed to 'can you tell me about the person, or people, you care for?' as it was acknowledge that some cared for more than one family member. As this change did not impact the main interview questions, the two pilot interviews were included in the main analysis.

A Dictaphone (Olympus Digital Voice Recorder DM-670) was used to record the interviews and NVivo was used to transcribe the interviews (analysis was conducted by hand).

5.3.4 Procedure

After initial contact, information sheets were provided and written consent was given by participants (and parents where necessary). Study materials and a follow up date to check progress were given to participants. Reminders about deadlines and the option to contact the researcher with questions were sent via email, text or phone call, depending on participant preference.

Young carers took between two and nine weeks to take photos (Mean = 3.5 weeks). Once complete, an interview was arranged within two weeks of photo development. Interviews were conducted in the homes of the young carers (N=10), a university (N=1) or a carers centre (N=1) and lasted between 21 and 105 minutes (Mean = 50 minutes). In six of the home interviews a parent was present for at least part of the interview.

The interview began after young carers had taken as much time as needed to look at their photos. In line with the focus on participant autonomy, young carers were asked to determine the order of discussion by selecting their favourite photo and were also asked to specify any photos they did not wish to be used in presentations or reports, these were marked with an 'X' on the reverse of the photo. The semi-structured interview schedule was used, asking questions until each photo had been discussed. The closing and debrief involved the researcher asking participants if they had anything to add or if they were surprised to have not been asked about something, which sometimes elicited further detail.

5.3.6 Data analysis

Sample size was not fixed ahead of data collection. Sample size is important, however additional factors such as data adequacy were considered (Vasileiou, Barnett, Thorpe, & Young, 2018). Therefore, sample size was determined on the basis of reaching code saturation and informational redundancy (Hennink, Kaiser, & Marconi, 2017; Lincoln & Guba, 1985).

Interviews were transcribed and briefly coded sequentially. By the tenth interview, no new codes or information were identified. To confirm code saturation and informational redundancy, two further interviews were conducted and briefly coded, after which sampling ended, providing a total sample of 12. After the final interview, transcripts were coded in more detail and underwent full analysis.

Data were analysed using a deductive thematic analysis and followed the phases proposed by Braun and Clarke (2006) as previously outlined (chapter three; 3.7.1). The photographs taken by young carers were a means to facilitating and collecting data via interview, therefore only interview transcripts were considered data and were analysed. Data were familiar to the researcher from conducting interviews, however transcription and reading of transcripts enabled further familiarisation. Transcripts were coded by hand and themes were identified, reviewed, defined and named with the aim of finding evidence of the three levels of protective factors conceptualised within the socioecological model of resilience.

Assessing the quality of evidence is a challenging but important aspect of research (Kmet, Lee & Cook, 2014), this is particularly the case in qualitative research as it is not appropriate to apply the well-known criteria (such as data assumptions) associated with quantitative data.

In order to assess the quality of the qualitative data and findings in this study, the checklist used to score quality in the studies included within the systematic review were used. The criteria developed by (Kmet, Lee & Cook, 2014) consists of ten points scored as zero (no), one (partial) or two (yes), with a maximum possible score of 20. The checklist covers the research question, evidence of and appropriate study design, clear context for the study, connection to a theoretical framework, clear description and justification for the sample, clear description of data collection methods, clear description of data analysis, use of verification procedures to establish credibility, conclusions supported by results and finally reflexivity of the account. The total quality score for the current study based on these criteria is 18 out of the possible 20.

The study methods and data were embedded within a pragmatic theoretical foundation and the analysis was strongly connected to the socioecological model of resilience. To ensure robustness in the researcher's interpretation and coding of the data, regular discussions with JB and JTC were held, to establish the appropriateness of the codes used and the themes identified.

Furthermore, reflectivity was an active process throughout the design, data collection and analysis of study. This was deemed particularly important due to the lead researchers own experience of caregiving. As such, precautions were taken to ensure that personal experience did not influence analysis or interpretation of the findings, including regular reflection on the process and discussions with JB and JTC, whereby alternative interpretations were considered and discussed.

5.4 Results

Through analysis 11 key themes were identified across the three levels of the socioecological model of resilience as shown in figure 5.1. A superordinate theme of distraction was also found.

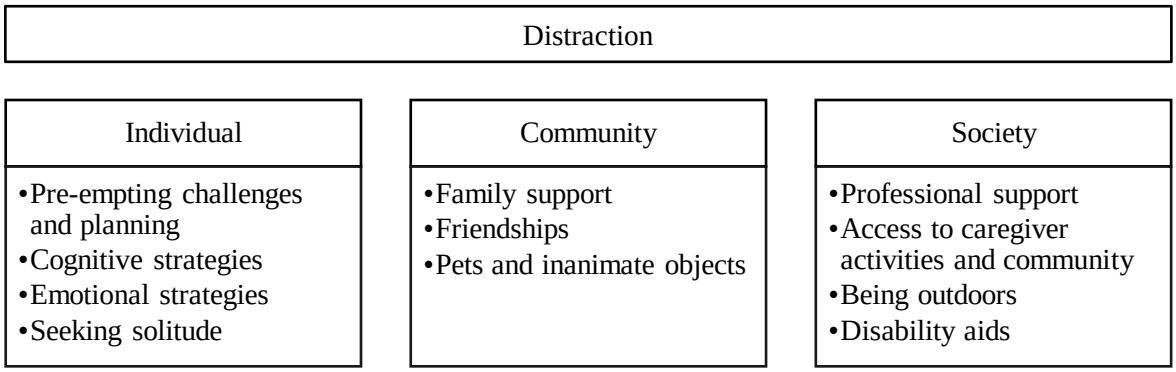

Figure 5.1 Themes identified across the three levels of the socioecological model of resilience (individual, community and society)

Four themes were identified on the individual level, three themes at the community level and four themes at the societal level. Each theme is presented below with extracts and example photos which elicited conversation about the theme. Some photographs containing identifiable information or people are not included as per the ethical considerations previously discussed in the methodology chapter of this thesis (chapter three; 3.9.2).

5.4.1 Individual

Individual factors described by young carers included pre-empting challenges and planning ahead for family life to run smoothly, cognitive strategies and processes which involved reframing in the form of benefit finding or acceptance, emotional strategies which enabled the modulation and expression of difficult emotions, and finally, the act of seeking solitude to cope.

5.4.1.1 Pre-empting challenges and planning ahead

Participants expressed thinking ahead was important and allowed plans to be put in place in case of emergencies, enabling family life to run smoothly. Examples included calling ahead to restaurants to ensure accessibility and arranging family schedules so care was always provided, particularly when the young carer was not available. This enabled relaxation and the opportunity to enjoy family days out or time away from home. For Bella, thinking and planning ahead involved the creation of an ‘emergency pack’ (Figure 5.2) containing essential items for her brother with profound autism.

Figure 5.2 Photo of emergency pack illustrating the factor of pre-empting challenges and planning ahead, at the individual level of socioecological resilience

This pack was carried with her at all times:

> *"So it's all stuff like little creams or plasters just in case he bumps his head or something and needs it…it's just a back up emergency pack…the majority of it's always in my handbag anyway just in case"* (Bella, F, 14)

Bella placed emphasis on 'just in case' and explained that planning for 'just in case' events was crucial for a sense of control when leaving the family home with her brother, enabling her to feel confident and prepared for all foreseeable events that may arise. Sometimes being forearmed meant finding more information about the condition of the person they were caring for to be prepared in emergencies. Penny describes the process she took to find information about her mother's condition by actively carrying out her own independent research:

> *"I was just going on google to find out… about fibromyalgia…I mainly find out in books and all different internet resources… it does give me a bit of relief because that then makes me feel ok knowing that this…might happen or…what like what will happen or might happen"* (Penny, F, 9)

Awareness of what might arise in the future allowed young carers to pre-empt potential challenges and with knowledge of the actions required in such circumstance's anxiety was reduced. This allowed young carers to feel they were in the best possible position to manage

situations effectively. Indeed, young carers described "just knowing" leading to feelings of "relief" after obtaining the information they were seeking.

5.4.1.2 Cognitive strategies

Young carers described cognitive strategies employed to manage and navigate their carer experiences which included benefit finding and acceptance. Young carers described reasons for employing these strategies, many of which centred on the desire to maintain a positive outlook and to feel in control of difficult or uncertain situations.

5.4.1.2.1 Constructing the benefits of caregiving

Participants described a process of identifying the benefits of their caregiving experience, which enabled a sense of certainty in themselves, their role and the meaning behind it, as well as providing them with confidence and a feeling they were on track. For some, the knowledge and skills gained from providing care for a loved one was a key benefit. In having such skills, Krissy felt in control of her current situation and her future prospects, as she had developed personal qualities such as empathy and patience as well as life skills which would help her in adulthood. Krissy had taken a photo of saucepans on the cooker (figure 5.3), explaining that acquiring skills such as cooking, cleaning and organisation provided her with the confidence she needed to leave home.

Figure 5.3 Photo of cooking equipment illustrating the factor of benefit finding, at the individual level of socioecological resilience, where Krissy felt learning skills such as cooking was a benefit of caregiving

Krissy felt that having these skills, which her peers did not have, was a benefit of her caring role:

> *"I'm good with money… I know what life consists of…bills and just taking care of yourself kind of thing, so like I think I'll be one step ahead with that and then like with money as well, I think I'm quite good at not like wasting it…"* (Krissy, F, 17)

For others, caring for a family member meant spending regular time with their family, more than their peers might, and though this involved caring responsibilities, family time was still considered to be highly important and valuable, as Bella explains:

> *"It's just sort of nice to think that I do see, I do literally see my family and get to go on holidays and actually spend quality time which rather than everybody else it's kind of good"* (Bella, F, 14)

Other young carers drew upon family related benefits such as receiving direct feedback from family members or directly from the person they were caring for, which helped them to feel secure and confident in their role. For Samantha, seeing her brother happy and achieving was a rewarding benefit as it reminded her she was contributing something positive to her family:

> *"Knowing that you're helping your favourite person… knowing that you're helping them achieve in life even though they can't really…just, seeing someone…with a disability or something, that's really struggling, be happy, is probably the best thing to be honest"* Samantha, F, 14

Samantha and Krissy represent a number of young carers who identify benefits in their caregiving and attribute qualities such as gratitude, empathy, patience and money sense to their experiences, allowing them to develop meaning, confidence and certainty within their caring role. This helps them feel in control of their role and thus helps them to manage and cope with their responsibilities.

5.4.1.2.2 Acceptance

Young carers actively used the cognitive process of acceptance, in contrast to seeking to control a situation, as some were deemed uncontrollable no matter how much understanding or benefit finding could be obtained. Samantha had accepted that she receives less attention from her family compared to her brother who has Rett syndrome and a high level of needs. Despite this initially being challenging she had learnt to understand and accept it where necessary:

> *"She [mother] has to be there for my brother more and I understand that…I understand that he needs more attention than me, and I'm perfectly fine with that"* Samantha, F, 14

Samantha also described acceptance surrounding her brother's condition, particularly when he was upset or in pain, as though this was difficult for her, she recognised that at times she was unable to provide support and needed to allow others to care for her brother:

"Something that makes me sad I put my brother crying, because my brother crying or just being in pain…Just feel really useless and…seeing something wrong with him that breaks my heart honestly, so it's just like, really hard to know, that you like, you've just got to let other people do their stuff" Samantha, F, 14

Other young carers discussed needing to accept circumstances external to the family and shared experiences of bullying, stigma and the perceptions of others, having a negative impact on their lives. As a result, Bella chooses not to disclose information about her caregiving as often peers did not understand and showed no willingness to try and do so:

"I just sort of just kind of take it on the chin and be ok you don't understand, I don't really want to explain it to you so just think what you want to think I don't really care" Bella, F, 14

For Bella, who liked to maintain control, moving towards acceptance and not caring about others' lack of understanding was challenging, but necessary, and represented the experience of other young carers. She added it was a 'normal' part of caregiving, suggesting in some instances, it was important to accept certain negative aspects of their lives, to cope with them.

5.4.1.3 Managing emotions

Young carers described sometimes being overcome with emotions such as anger, anxiety, sadness and grief for a range of reasons, such as their caregiving role but also friendship or school difficulties. A range of strategies were evident for managing this, including the use of breathing techniques which prevented emotions from becoming overwhelming. Penny managed her anxiety by breathing slowly and Tobias' mum encourages him to keep breathing when he is upset, helping him calm down and feel able to cope:

"Some people when they get upset someone else tells them to keep on breathing…which is what mum once done to me… she started telling me to breathe and I started and then after like five minutes of breathing I was like, I feel a bit better now" Tobias, M, 8

Technology such as video games, mobile phones and tablets, were considered as a helpful tool when managing emotions, allowing young carers to calm down, relax and distract themselves from the emotions associated with caregiving. Arthur found video games a helpful distraction from his emotions and his brother's challenging behaviour:

"I like playing on my x-box because it's like you get distracted when you get like angry like your brother's hitting you and all that you can just calm down and play on the x-box and calm down and play with him again" Arthur, M, 9

Young carers also took steps to healthily express and externalise emotions. Being physical allowed expression of anger around the carer role but also bullying or friendship difficulties. Samantha attended cheerleading, dance and athletics and found physical exertion a productive way to release anger and frustration. Tobias found hitting his bean bag (Figure 5.4) was helpful, especially as there was no negative outcome to this behaviour, unlike hitting a school friend.

Figure 5.4 A photo of a bean bag illustrating the factor of emotional strategies, at the individual level of socioecological resilience, whereby Tobias used his beanbag to let out anger or difficult emotion

"Sometimes when I get a bit mad at school I just like to come back home and because um, I won't be able to break the bean bags I start punching them…because when I'm angry I usually start getting too rough at school but with this I can get as rough as I want, because it won't do anything to anyone, and it's too strong to break" Tobias, M, 8

Creative expression was valued as a way to express, transform and externalise emotions. Sophia expresses emotion creatively, providing her with a physical representation of her emotions which she can use to tell people how she is feeling and receive support; she sometimes found this easier than introducing her feelings into conversation:

"Music, drama and photography…that's pretty much how I express…my feelings and get them out and … like when I'm sad or… angry maybe" Sophia, F, 14

Young carers described a need to manage their emotions, through inhibiting them or seeking to reduce their intensity, but also had means to express their emotions. Creative and physical means were the main outlets, which also offered opportunities for social connection and reduced the possible negative impacts of expressing emotion in unhealthy ways.

5.4.1.4 Seeking solitude

Young carers emphasised the importance of actively seeking solitude and withdrawing from social interaction, including family, as a way to manage their mood and energy. Seeking solitude was an instinctual reaction to challenging circumstances; retreating and being alone allowed the time to process emotions or situations that had arisen. Samantha describes her bedroom (figure 5.5) as a place of refuge when things are difficult with her brother:

> *"If I get bad news or anything, I'm like straight away in my room…if there's something bad happening with my brother or something, and I can't help…I just go to my room and wait…it's like my little comfort zone"* Samantha, F, 14

Figure 5.5 Photo of young carer's bedroom illustrating the factor of seeking solitude at the individual level of socioecological resilience, whereby Samantha sought time alone in her bedroom

Samantha also described her bedroom as somewhere she could be without 'nagging'. Other young carers relaxed with music, a film or lying down, without the requirement to do anything else. Krissy describes such an occasion:

> *"I quite like just sitting down and listening to music by myself and … relaxing doing that… it just like, makes me feel like, I'm just here, I've got nothing to do kind of thing and it's just nice to sort of sit there and listen to someone else"* Krissy, F, 17

Young carers emphasised the importance of connection with others, but also simultaneously valued the opportunity to withdraw. One young carer described it as 'not isolated, but…away from people' providing quiet space to relax and escape daily life and obligations.

Overall, young carers demonstrate a number of internal factors which act as personal resources within the challenges of their caring situation, or facilitate benefits such as relaxation, down time or a more positive outlook. For some these internal resources were a natural response and for others, they required the suggestion or guidance of others.

5.4.2 Community

Young carers drew upon community factors enabling them to cope with challenges in a positive way. Community factors are those related to the immediate community surrounding an individual including family and friends. Primarily, the factors identified within interviews centred on social support, of which there were numerous sources (family, friends, pets and inanimate objects) and types (emotional, practical and indirect).

5.4.2.1 Family support

Family members were a key source of emotional and practical support to young carers. For young carers caring for a sibling, this was often their parents. Despite the pressure parental carer's also face, they were valuable sources of support for the young carer. Samantha explains how this derives from a shared experience of caregiving:

> *"The person I rely on for support is probably mum, cos she knows everything, I literally tell her everything… she's in the exact same boat as me, so it's nice to just sit down, have a chat with her…and she's like really good at supporting and everything, because she has been through a lot with like my brother"* Samantha, F, 14

Connection and time spent with family members often provided mental and physical distraction. Those caring for a sibling noted the importance of spending time alone with their parents. When Bella's brother was with their father, she spent time with her mum and they did activities they would not normally be able to do, which distracted her from caregiving thoughts:

> *"When he's not here we tend to go out more and just do day trips just to kind of take our minds off everything and just do day trips that we might not have been able to do"* Bella, F, 14

Siblings were sources of support for those caring for a parent, often sharing responsibilities and understanding of the role. Sophia and Penny care for their mum and also

provide each other with emotional support, especially through humour and laughter, which created a lighter family atmosphere:

> *"She'll [sister] cheer me up quite a bit, just being her to be honest, makes me laugh and like um, if…I make a silly comment the family will make a joke out of it which makes me laugh as well"* Sophia, F, 14

Emotional support from family members also came in the form of recognition and appreciation, helping many young carers to feel noticed and valued. Praise and gratitude came from family members who also helped with caregiving, but sometimes it came from the person being cared for. This recognition was especially valued and helped young carers feel their efforts were worthwhile; particularly when difficult caregiving situations required greater motivation or confidence. Bella described occasions when her brother showed gratitude (figure 5.6).

Figure 5.6 A photo of a message of support from a carer's sibling, demonstrating the factor of family support at the community level of socioecological resilience

These demonstrations of love and value were especially important when they were spontaneous and unexpected:

> *"Every now and again…I'll just kind of turn up and there will be like a poster…when it's just sort of, spontaneous, that's really nice of you and it's kind of like…happy because it's like, oh you've just done that because like, obviously he's grateful for stuff…just little pieces here and there just sort of make it all worthwhile and like oh ok it is like good that I'm doing it…cos you kind of, see it and you're like thank you, it's like being noticed"* Bella, F, 14

Emotional support predominantly came from immediate family members, but tangible, practical support was typically provided by extended family. Krissy describes the help of her aunty to complete paperwork ensuring the correct benefits were in place after a hospital visit and her mother's initial diagnosis of Multiple Sclerosis:

> *"My aunty helped with sorting my mums benefits out…so she's getting the right amount of money through and then… they did…a card that's linked to my mums account as well so like we've got one where we can go like food shopping and stuff"* Krissy, F, 17

Transport provision was highlighted by some young carers as most did not have their own transport. Many did not feel comfortable taking public transport or timings were inconvenient, causing delays in returning to caregiving duties, contributing to anxiety and worry. The assistance of Samantha's grandfather allowed her to attend activities and without this support she would be unable to socialise or develop skills at evening events:

> *"With getting there [cheerleading] I normally get my Grampy or I walk home by myself"* Samantha. F, 14

The examples above demonstrate that wider family can positively impact the lives of young carers, and can act as gateways to services or activities that would otherwise be difficult to access. Furthermore, this indicates that social support can facilitate the development of, or access to, further factors that enable young carers to cope effectively with their situation.

5.4.2.2 Friendships

Young carers frequently referenced the importance of supportive friendships and the opportunities they provided to receive guidance, emotional support and a chance to 'switch off' from caregiving. Being able to 'just talk' to friends about feelings, emotions, thoughts and difficulties was an important factor, particularly when caregiving was challenging, for example due to relapse or accidents. India found it important to have friends who provided support when asked but also actively took the time to ask how she was, as sometimes starting conversations was difficult:

> *"I talk to friends mostly, cos they're good with talking to…they know to…check up on me now and again which is really nice…it's nice to have someone like, that's there for you"* India, F, 18

Friendships that provided emotional support, humour and reassurance were important when difficult periods were experienced. Sophia's friends help her to feel better when she had a bad day:

> *"My friends support me quite a bit…they cheer me up if I'm sad and they like help me through my rough days…making me laugh and…like reassuring myself…"* Sophia, F, 14

Sophia emphasises social support is a reciprocal process, which can sometimes provide positive distraction, but can also come at the cost of not tending to her own needs or emotions:

> "Like I help my friends through their problems as well…if my friends feeling like depressed or something I'd help them which also like kind of takes my mind off my problems but it also like kind of makes them a bit worse because I'm thinking of my friends more than I'm thinking of me" Sophia, F, 14

For some, connecting with friends in person was difficult due to the restrictions caregiving placed upon them. In such circumstances, technology was used to access social support (figure 5.7).

Figure 5.7 Photo of a mobile phone, illustrating the factor of friendships at the community level of socioecological resilience, whereby the phone is used to contact friends and seek support

Krissy sometimes found it difficult to steer conversation to her current situation when with friends in person, but when using instant messaging found it easier to express how she was feeling:

> *"With close friends I can… send them like a message that I'm feeling crap and they'd be like…you can just talk about it, even if we were talking about something else, it's like*

easy to go onto that topic because they understand about it all… I find it easier than telling someone if we're together I feel like crap" Krissy, F, 17

Many young carers valued friends who were supportive, understanding and had the ability to cheer them up. These qualities enabled them to open up about their feelings in the face of concerns about stigma or bullying. Meeting and making friends with other young carers was important, where similar to family members, there were shared experiences and responsibilities. Close friendships could develop based on mutual understanding:

"It's like going to see people who are in like the same boat as you kind of thing… when I try to talk to my friends about stuff they don't really understand, but if you talk to people who go there they understand because they're basically going through the same thing, so that's really good" Samantha, F, 14

"It's like people who are in… the same state as me…the same, scenario that I'm in and like they've also cared for a family member so they know…how it feels" Sophia, F, 14

Overall, friends were able to provide support beyond that of the family and despite some challenges surrounding time and travel, many young carers actively sought out and nurtured friendships.

5.4.2.3 Pets and inanimate objects

In addition to support from family and friends, pets and inanimate objects also afforded emotional support to young carers (figure 5.8).

Figure 5.8 Photo of young carer's dog and soft animal, illustrating the factor of pets and inanimate objects on the community level of socioecological resilience, whereby Olivia receives support and comfort from both her dog and her cuddly toy

Often, pets were considered family members and seen as vital sources of emotional support for young carers, providing comfort and a reliable presence. Penny recounted how her dog knows when she is in need of support and can be relied upon. Similarly, Olivia describes her cat, who sleeps on her bed, as family, providing comfort in difficult times:

> *"My dog, so [dog] is there so I can rely on him…we are basically family…he is very special to us … we can rely on him…if I am upset he just runs to me and like gives me support"* Penny, F, 9

> *"She [cat] comforts me because I used to be really afraid of the dark and leaving mum downstairs on her own…but now my cat has…started to sleep on the bed with me…she's a…comfort, it's a bit like she's my mum"* Olivia, F, 9

Treasured toys were a source of security for the youngest of the participants, providing comfort and support. Young carers referred to their reliability and a sense of friendship when their toys were close by. Penny had 'a very special teddy' and Tobias had a cuddly toy who was sometimes a substitute for his friends, making him feel he had someone to rely on:

> *"I usually don't go to sleep without him [cuddly toy]…sometimes when I'm a bit upset I take him to school, so…when I'm upset then I've still got him…when I'm near him it makes me feel like that I've got my friend with me…I can keep him at home because I can't keep my friends here but I can keep him here"* Tobias, M, 8

Despite pets and inanimate objects being unable to verbally communicate, they were still key sources of support for young carers indicating that social support is not necessarily a reciprocal process.

The factors within the community level provide sources of support, in the form of family, friends, pets and inanimate objects. Often, but not always, these sources of support are close by or easily accessible, enabling these factors to act as resources which enable them to share how they are feeling, receive emotional support and obtain practical assistance regarding aspects of their caregiving or social lives.

5.4.3 Society

In addition to individual and community factors, there were wider societal factors (beyond that of family, friends and social support) young carers drew upon. These included professional support and access to carer activities and community, but also environmental factors such as being outdoors and the provision of disability aids.

5.4.3.1 Professional support

Young carers described receiving emotional and practical support from professionals and many emphasised the importance of being able to 'just talk' to someone and being heard in a safe environment. For some young carers, this support was via professional counselling which was typically accessed via local health services and enabled them to explore their feelings surrounding their caregiving and other challenging aspects of their lives. Penny sought support from her local Child and Adolescent Mental Health Service for anxiety and was able to 'talk to them' but was also given 'techniques' to help her cope. School counsellors were accessed in some cases and were sometimes more convenient, particularly when taking into account transport and time restrictions:

> *"I started having like counselling sessions in school…which did help…I used to get upset by it like a lot…now I'm not like kind of crying about it all the time… it was just like high emotions…whereas now I can just kind of, like, talk about it and…it's easier…the counsellor herself she was just like really friendly"* Krissy, F, 17

The friendliness and approachability of professionals was vital for young carers to trust and feel supported. Contact with professional support was often face to face, however some young carers described contacting support outside of formal sessions. Bella was able to talk to her support worker at young carer's events, but also electronically if necessary:

> *"I've got a support worker… who sort of pops into school now and again and is at all…the activities I do so if I need to say can I just talk to you for five minutes then we'll go into a seperate room and just talk…if I need her I can email her, call her, text her"* Bella, F, 14

Personal characteristics of the professional, alongside confidentiality and access were considered key elements of professional support. Reliability was important for emotional support, but was considered even more so for practical professional support. Young carers described receiving practical support from support workers, formal carers and teachers, which relieved some of the pressure they faced and shared some of the responsibilities they needed to manage. As all young carers were in formal education, many described teachers providing support and Krissy explained she was given special consideration surrounding homework and deadlines which was helpful. Samantha described how understanding teachers provided alternative arrangements, enabling her to manage both her education and her caregiving, by considering the time of events, offering after school activities and being understanding around lateness or incomplete homework:

"I have like really nice…teachers that are there for me and…understand if I can't get home or can't get in…my mum called up the school and…talked to them about if I could have help with after school clubs because sometimes I can't make them…they understand if I am late sometimes, or if I need homework a day later so that's really good… my teacher understands that I can't get places" Samantha, F, 14

Sometimes support from teachers is indirect and focusses on the person being provided with care and this was particularly true of young carers who had siblings at the same school. Teachers were able to provide support for the person receiving care and in doing so, relieved the young carer of responsibility, either temporarily or for the school day. This often meant young carers did not need to worry about their sibling throughout the day. For Arthur, the teacher handled situations that may be difficult for him to manage on his own. Again, understanding was an important element of this support:

"Yeh they [teachers] know that I help out with [brother] one of the teachers at school… normally helps [him] to calm him down… it's actually quite nice because she normally teaches me so if like [if he] starts hitting me… she will just get [him] away from me and calm him down and then I can just go and start playing again" Arthur, M, 9

Indirect support also came in the form of formal carers, whereby the primary recipient of support was the person being cared for, but this had an indirect impact on the young carer by giving them an opportunity to relax, socialise or mentally have a break from caregiving. In many instances, young carers had to manage schedules ensuring they were home at certain times and this placed restrictions upon their time to socialise with friends or attend after school activities. For India, who cared for her brother, support from a professional carer for a limited period gave her the freedom to spend time with friends and have a break from caregiving:

"My brother got, support from one of those companies where people have carers …I remember saying that I just liked hanging out with my friend after school…but I couldn't because I had to get a train back… I just wanted Friday nights after school to fester in town and… they got the whole company thing going…which I meant I could have a bit more time which was really cool" India, F, 18

Formal carer arrangements varied from a one off, to short and long term provision of support. Essentially, the provision of such support, in addition to that provided by teachers, support workers and counsellors enabled young carers to take a break from their caregiving or to diffuse some of the pressure they were under, enabling them to access other factors which helped them to manage their carer experience.

5.4.3.2 Access to carer activities and community

All young carers interviewed had access to activities and a community of carers through carers' centres or charities and reflected upon the benefit of being able to attend events such as arts courses (figure 5.9), day trips and residential camps.

Figure 5.9 Photo of arts activities provided by a carers' centre organisation, demonstrating the factor of access to carer activities and community, at the society level of socioecological resilience

Despite expressing pride in their role, challenges were faced and it was important for young carers to take a break and step away from their caregiving to enjoy activities with friends and other young carers, away from the family unit. Many believed this enabled them to successfully care and have 'more to give' to their loved one when they returned home. Many young carers expressed appreciation of events hosted by their local carers' centre which provided the opportunity to socialise, relax and learn new skills. There was a strong emphasis on fun, meeting new friends and having a break:

> *"So young carers…they um just give you time to relax and they just set up places where you can have fun and you can take a bit of a break off of caring and get to meet new friends…that helps a lot"* Penny, F, 9

> *"You get a break from caring and you can meet up with other friends that you've probably never met before"* Charlie, M, 10

Meeting other young carers enabled them to develop a sense of being part of a community where they were 'not alone' and others 'understand' them in ways non-carers cannot. Opportunities to be involved with residential trips were especially immersive. Sophia described meeting new people at a young carer's festival who she remains friends with. Despite the value in these experiences, there were also challenges surrounding them due to leaving the family member they were caring for. Doing so typically led to feelings of anxiety and worry and

for some this tension was very difficult to manage as they had to weigh the cost of leaving their family member and the distress of doing so, with their desire to meet new people and have a break. Sophia, who described herself as very adventurous finds it difficult to leave her mother due to the lack of control she has in such situations were anything bad to happen:

> *"R: So what is it like leaving mum when you go away?*
> *YC: … it's quite scary cos I don't know what's going to happen"*
> (R = Researcher, YC = Sophia, F, 14)

Overall, though stepping away from the carer role was important, it did not come without challenges such as worry or sadness when leaving their loved one. When away from family, support from friends and professionals helped them to manage their anxieties and made events more enjoyable.

5.4.3.3 Being outdoors

A further community factor was being outdoors. Nearly all participants reflected on this aspect of their lives. Unlike being in the family home, being outdoors, predominantly for exercise and socialising, provided a sense of freedom from caregiving but also more generally. Many young carers described feeling the family home contained their caregiving and all the stress that came along with it, however being outside provided freedom, wellness and calm. Charlie felt when you are outside "you're basically free from everything in your house" and many other young carers expressed similar sentiments. Despite this positive association and the benefits of being outside, a number of the young carers explained being outdoors was somewhere they didn't spend a lot of time but wanted to. For some, being outdoors did not always require going far (figure 5.10):

> *"My garden…I don't spend much time there…I just want to get out there…in the garden more… I like being quite adventurous and out, I'm quite an outdoorsy person… the feeling of being free and being out there, which I like…that's what I enjoy about going on some camps that I can just get to be outdoors and it's fun"* Sophia, F, 14

Figure 5.10 Photo of young carer's garden, demonstrating the factor of being outdoors, on the society level of socioecological resilience, whereby being outdoors offers a sense of freedom

Some young carers such as Krissy, clearly explained the contrast between the freedom of the outdoors and the restrictions of being inside:

> *"Somewhere I would like to spend more time…my garden… not just in my garden but like outside more generally…going out on my bike or that kind of stuff and just like walking…being outside for a little and that kind of thing…I think it's just the fresh air because like if I'm inside a lot I just get like uh…it's just like kind of free…even like, when it's cold it's like, kind of nice…compared to when you're like inside"* Krissy, F, 17

Similar to the previous theme, being outdoors, and leaving the family home, could cause anxiety and worry, however for the most part, these feelings were manageable. Being outdoors enabled a sense of freedom that could often not be reached when indoors.

5.4.3.4 Disability aids

Disability aids were sometimes provided by the National Health Service or charities, but were often purchased privately. This equipment helped with caring tasks that were challenging. Samantha described some changes made in the family home which made providing care to her brother easier, more efficient and ultimately safer, given her brother was growing and getting heavier:

> *"We got the wet room six years ago…and … the chair lift… it's made a big difference because you can't lift him into a bath…so having a shower where he can stand up and you can just rinse him is really good…he walks upstairs but he doesn't go downstairs, so we use the chair… so that's really good because otherwise we'd have to carry him… he looks small but he's really heavy"* Samantha, F, 14

Indirect support via disability aids were not always in the form of large or structural changes within the home and sometimes were as simple as a walking stick (figure 5.11).

Figure 5.11 Photo of young carer's parent's walking stick demonstrating the factor of disability aids at the community level of socioecological resilience

For Tobias, his mum's walking stick gave him peace of mind that his mum had help with her mobility and this allayed fears and anxieties about her well-being:

> *"What makes me happy about mum's walking stick is that it helps her out…because she has to use it and it makes me feel a bit more better that she's got something to help her use when she doesn't have a buggy"* Tobias, M, 8

In these instances, the use of disability aids as a permanent or portable feature of the surrounding environment, offered ease for the cared for person but also made life easier for the carer themselves.

Overall, societal factors ranged from professional support of individuals but also equipment such as disability aids. Carers drew upon their wider carer community for support and connection, in addition to being outdoors for freedom and having a break from their caregiving. These factors go beyond family, friends and the place they call home, to create a network of wider support and access to resources, enabling them to feel they can cope with and manage their caregiving situation.

5.5 Discussion

The aim of this study was to deductively explore potential protective factors in a sample of young carers, through the use of photo elicitation interviews. The research identified 11 factors within the three levels of the socioecological framework and thus indicates that the framework proposed by Windle and Bennett (2011) and used in research with adult and elderly carers, can be applied to a young carer sample. These findings will be further discussed in detail in relation to the socioecological framework in the overall discussion (chapter 7; 7.6.5).

5.5.1 Individual

Four factors were identified at the individual level. The first, pre-empting challenges and planning, supports previous research which found task-focussed, active and cognitive coping were linked to resilience in adult Alzheimer and dementia carers (Dias et al., 2015; Garity, 1997). Second, the cognitive process of benefit finding (actively seeking to identify positive aspects of caring), was identified as a strategy employed by young carers and initial research into this area has found young carers describe benefits of their role including social recognition and family support (Cassidy et al., 2014). A third factor, seeking solitude was identified. The adult and elderly carer literature predominantly deems social withdrawal to be a negative factor (Ekwall, Sivberg, & Hallberg, 2004; Sawatzky & Fowler-Kerry, 2003) as it limits access to social support and connection which is linked to positive outcomes in carers (Beck, 2007; Haley, Levine, Brown, & Bartolucci, 1987; Miller et al., 2001; Pakenham & Bursnall, 2006; Ruiz-Robledillo, De Andrés-García, Pérez-Blasco, González-Bono, & Moya-Albiol, 2014). The contrasting findings in this study demonstrate the inherent difficulty of categorising factors to be either protective or risky, and suggests context is an important consideration as highlighted by Luthar et al (2000). The need for solitude and social withdrawal may be a wholly adaptive approach to managing mood and energy in the busy lives of young carers.

Finally, emotional coping strategies used by young carers were identified and thus may act as protective factors. The literature surrounding emotional coping is mixed, but mostly, in adult and elderly carers, it suggests adopting emotional coping strategies is less effective than problem focussed strategies (Pakenham, 2001) and is associated with poor adjustment outcomes (Figueiredo et al., 2014; Mausbach et al., 2013; Ruiz-Robledillo & Moya-Albiol, 2013; Sander et al., 1997). There is evidence to suggest emotion-focussed strategies can be helpful, by venting emotion or crying (Azman et al., 2017; Figueiredo et al., 2014). Young carers developed ways to manage or express their emotions and were able to make decisions about the most appropriate ways to do so. This contrasts with literature suggesting carers are less able to regulate their emotions compared to controls (Ruiz-Robledillo & Moya-Albiol, 2013), further demonstrating what might be a risk factor for general populations (e.g. social withdrawal, emotional expression) may serve as a protective factor in another population (Luthar et al, 2000). This supports the argument that a variety of coping strategies and protective factors may be necessary to protect against risk factors and promote resilience (Pakenham, 2001; Southwick et al., 2014).

5.5.2 Community

Three factors were identified within the level of community. Social support from friends and family, has been identified as a protective factor against stress and it is therefore unsurprising that these factors were raised by young carers in this study (Dias et al., 2015;

Greeff, Vansteenwegen, & Ide, 2006; Wilks & Croom, 2008; Zauszniewski, Bekhet, & Suresky, 2010). Luthar (2000) argues relationships are the foundation upon which resilience is built and Rutter (1979) highlights maternal warmth and a positive family atmosphere are also important for childhood resilience, factors that featured within the interviews for this study. Dias and colleagues (2015) found satisfaction with social support influenced resilience. This did not explicitly feature in this study, however young carers did highlight friends who were and were not helpful, and at times expressed frustration regarding this.

Finally, pets and inanimate objects were important to young carers, a factor which has not yet been explored in carer resilience research. General research however has found pets and companion animals can provide the necessary relational bonds required for resilience within a family context (Walsh, 2009).

5.5.3 Society

Four factors were identified at the level of society. Firstly, further sources of social support were identified via professionals such as teachers and social workers. Secondly, the provision of disability aids is a factor that has not previously been discussed specifically within carer resilience research. These factors essentially provided freedom and respite or made a task easier and though intended for the person receiving care, they assisted the carer themselves, supporting Werner and Smith's theory (1982) that protective factors can be both direct and indirect. A final factor was being outdoors and the freedom it brought which is not yet referred to within carer literature. General population based research has identified the physical and mental health benefits of being outdoors and in nature (Mutz & Müller, 2016, Mantler & Logan, 2015). Rigorous research, clearly measuring the concept of resilience in relation to being outdoors is yet to be conducted.

5.5.4 Commonalities across themes

Across the levels of resilience factors and themes identified, there were common outcomes associated with specific strategies or resources which warrant discussion.

Distraction was often facilitated by family members, friends and activities. Similar to social withdrawal, there is overwhelming literature suggesting distraction is associated with negative outcomes in adult carers (Figueiredo et al., 2014; Haley et al., 1996; Ruiz-Robledillo et al., 2014; Sander et al., 1997). Despite this, many young carers emphasised the importance of distraction in managing their role and the emotions that arise surrounding it, this further demonstrates the diverse nature of both protective and risk factors and the importance of context (Luthar et al, 2000).

A number of factors allowed carers to step away from their carer role and take a break, through seeking solitude, socialising, professional support, activities or being outdoors. Evidence suggests a positive relationship between respite from caregiving and resilience, coping

and quality of life in adult, elderly and parental carers (Donnellan et al., 2015; Jeon, Brodaty, & Chesterson, 2005; Remedios et al., 2015; Zarit, Stephens, Townsend, & Greene, 1998).

Reliability was important for young carers when it came to managing their carer experience and was a quality appreciated in family, friends, pets and professionals. Additionally, disability aids were only considered beneficial when reliably working and not causing additional difficulties or disruption.

Finally, many factors were related and interdependent, with the presence (or absence) of protective factors facilitating or hindering access to further resources or protective factors. An example includes, transport provided by family members enabling attendance at activities which facilitate emotional expression, social support and a sense of community. It is therefore important to recognise protective factors do not always operate in isolation, and numerous factors are often required to promote or develop resilience, highlighting the complexity of resilience itself. There are likely to be factors which inhibit or hinder resilience and though this study did not aim to identify these factors, it is an important consideration to make when considering future work or implications.

5.5.5 Strengths and limitations

This research supports the relevance of the socioecological model of resilience in young carers. This innovative research was the first to adopt a photo elicitation method with a young carer population, and to our knowledge, is one of a handful to use it in an informal carer population. This method enabled in depth, rich and diverse data to be collected, and offered a level of engagement and autonomy for young carers within the research process that many other methodologies cannot.

Anecdotally, young carers and their parents reflected on the process of taking and discussing photos as a helpful and enjoyable experience which allowed children to acknowledge their role, take pride in it and make space for it within the family home. Though parents did not formally participate in the interviews, on some occasions they were present and many highlighted the interviews allowed their child to speak openly about their experiences in ways they had not previously done, both within the interview and the family home. Though anecdotal and not recorded, these comments support the process of taking photos and discussing experiences as a positive one, which acted as an intervention in itself for families. This demonstrates the importance of choosing methods that are accessible, appropriate and beneficial to participants (Cappello, 2005).

Disposable cameras were chosen over digital or phone cameras to reduce the risk of carers deleting or editing photos, however there were some practical challenges with their use. Some young carers had not used a disposable camera and were not aware of issues such as using the flash or the range at which to take photos. In addition to some cameras also having

faulty winders, this meant some photos were unclear or blank. Despite this, photos were still provided and notes written by young carers were still discussed during interview.

It is important to consider sample size and characteristics. Twelve young carers participated in this study. Despite code saturation being reached, various life stages being covered (e.g. those in primary, secondary and further education) and a diverse range of conditions included (ranging from physical illness, mental illness, degenerative disease, terminal illness and illness that fluctuated), interviews were confined to a limited geographical area in the South West of England. Young carers were predominantly female and supported by carers' organisations. This data may therefore represent a very specific experience of caregiving. This is a notable limitation, given participants emphasised support from organisations. Young carers who are isolated and not being provided with support are difficult to access and thus recruit for participation. Nonetheless, they may have a very different experience of their caregiving, and thus, the findings of this study and the experiences described by participants may not have representational generalisablity, whereby the findings cannot be generalised to the overall young carer population.

5.5.6 Future research and applications of the work

This study has identified factors with the potential to influence resilience outcomes and further investigation is needed. The exploratory nature of this study is not a limitation but a vital first step to researching these issues with young carers. This study was based upon a very limited carer resilience literature and to date there has been only one study investigating the experiences of young carers from the viewpoint of resilience, therefore this study offers a further starting point to do so.

The very limited research assessing resilience in young carers has been based upon a body of evidence gained from studying adult and elderly carer resilience, or other vulnerable youth populations. These findings allow future research to be based upon the direct experiences of young carers as they describe them, rather than previous literature unrelated or irrelevant to young carers. This is important, as young carers are a population who given their developmental stage, face very different challenges to those who are adult or elderly carers.

A vital next step would be to quantitatively measure these identified factors to determine whether there are any relationships to a psychometric measure of resilience providing more concrete and causal evidence. It would also be beneficial to explore these measures alongside biomarkers of stress to determine if there is any impact on overall resilience in young carers. Doing so would allow for objective evaluation of stress, resilience and coping (Southwick et al., 2014). Indeed, this would address Rutter's (1979) call for further research in this area and for a stronger focus on the biological aspects of risk which are frequently neglected in resilience research.

Despite the need for further research, these findings do have important applications. Factors identified can guide those supporting young carers such as charities or organisations, to determine if these factors are important to their service users and thus aim to deliver services aligned with them. For example, offering opportunities for young carers to take a break whilst incorporating or encouraging elements of social support, being outdoors or emotional expression.

5.5.7 Conclusion

Overall, this study provided valuable insight into the potential protective factors present in young carers where previous literature has focussed on outcomes or adult and elderly carers. Findings support previous literature, but also add an understanding of the unique ways these factors operate in young carers. The use of photo elicitation allowed for the views and experiences of young carers to be represented, whilst also finding support for the application of the socioecological model of resilience in young carers. This study contributes new knowledge regarding young carers' experiences and is valuable in and of itself, but also offers a basis for future study. Ultimately, the identification of factors that promote or develop resilience will support the development of well-informed interventions which harness these protective factors and lead to more resilient outcomes for young carers.

5.6 Chapter summary

This chapter has presented the background, method and findings of a photo elicitation study conducted with 12 young carers between the ages of 5 and 18 years old, recruited from Carers' Centres in the South West of England.

Eleven total themes were identified within the resilience factor categories proposed by Windle and Bennett (2011). Four themes were identified on the individual level (pre-empting challenges and planning ahead, cognitive strategies, emotional strategies and seeking solitude), three themes at the community level (family support, friendships, and pets and inanimate objects) and four themes at the societal level (professional support, access to carer activities and community, being outdoors and disability aids).

Discussion highlighted that many of these factors have been identified in adult and elderly carer populations but also noted additional factors that have not yet been studied within the carer literature. Strengths, limitations and applications of the work have been discussed and suggestions for future research have been proposed.

Chapter six: Pathways to psychophysiological resilience in young carers; mapping the impacts of chronic stress

6.1 Chapter overview

This chapter presents the background of a quantitative study conducted with a sample of young carers and age-gender matched non-carers. The method is described, covering the main measures of questionnaires and hair samples, before the findings of the study are presented and discussed in relation to previous literature and implications. The study builds upon the literature review, systematic review and interview study as presented in previous chapters.

Fifty young carers and 48 age and gender matched non-carers between the ages of 11 and 18 years took part in the study, providing hair samples for cortisol analysis and completing a series of questionnaires. Data were analysed using a combination of independent sample t-tests, Pearson's correlation, hierarchical regression and moderation analysis. The findings are presented in detail in this chapter and their implications are discussed with reference to the general caregiving literature and where it exists, the young carer literature. Consideration is made of the strengths and limitations of the methods, recruitment techniques and overall sample.

6.2 Introduction

As established thus far, resilience is predominantly defined by theorists as an interaction between an individual experiencing stress (or a risk factor), internal factors and external environmental factors, with those promoting positive outcomes and resilience considered protective (Rutter, 1979). Resilience can involve both psychological and physiological adaptation (Kneebone & Martin, 2003). The adult and elderly carer literature has identified a number of protective factors that promote psychological and physiological resilience in the face of caregiving, a recognised chronic stressor. These factors include social support (Baron et al., 1990; Kiecolt-Glaser et al., 1987), cognitive coping strategies (Donnellan et al., 2015), benefit finding (Cassidy, 2013; Cassidy et al., 2014; Pakenham, 2005b), and self-efficacy (Zhang, Edwards, Yates, Li, & Guo, 2014).

Although research surrounding elderly carers and physiological outcomes are relatively conclusive and have identified that elderly carers typically show elevated cortisol levels and poorer neuroendocrine and immunological outcomes than non-carers (Kiecolt-Glaser et al., 1996; Kiecoltglaser et al., 1991; Vedhara et al., 1999; Vitaliano et al., 1997), research with younger adult populations is more mixed.

In evaluation of research with elderly carers, Vedhara et al (2002) raised the issue that the elderly have a natural decline in immunity as they age and therefore conducted research with non-elderly carers (with a mean age of 33 years). It was found that the immune dysregulation

typically seen in elderly carers was not implicated in younger adults. Further research supports these findings (Gallagher et al., 2008), whereby S-IgA (secretory immunoglobulin A; a marker of immune function) secretion was found to be lower in carers than age matched controls, but only in those who were categorised as elderly (M = 63 years), rather than middle aged (M = 44 years) or young (M = 24 years). Furthermore, research exploring parental carers of children with autism and attention deficit hyperactivity disorder (ADHD) identified that compared to 22 parents of typically developing children, 56 carers scored higher on measures of psychological distress and showed higher concentrations of inflammatory biomarkers, however they did not show different patterns of diurnal cortisol secretion (Lovell et al., 2012a). These findings demonstrate that as carer age decreases, findings surrounding the physiological impacts of caring are less conclusive. Some researchers have suggested that poor physiological outcomes in older carers may be due to a combination of chronic stress and immunosenescence, and findings in non-elderly carers may indicate a possible physiological adaptation or resilience (Graham et al., 2006; Kiecolt-Glaser et al., 2003) as a result of lesser accumulated life stress and therefore less allostatic load.

Within the field of young carers, efforts have been made to establish the psychosocial factors which may contribute to positive young carer outcomes, including social support, coping, carer context, appraisal, mental health literacy, benefit finding and social connectedness (Cassidy et al., 2014; Forrest Keenan, Miedzybrodzka, Van Teijlingen, McKee, & Simpson, 2007; Fraser & Pakenham, 2009; Pakenham et al., 2007). In particular, resilience and benefit finding have been identified as mediators of mental health outcomes in young carers (Cassidy et al., 2014). Though progress has been made with regard to psychosocial outcomes in young carers, physiological outcome research with young carers is scarce (Lovell et al., 2012a). There have however been studies which have explored children living with parental illness or disability such as HIV/AIDS (Chi et al., 2015), Rhematoid Arthritis (RA; Turner-Cobb, Steptoe, Perry, Axford, et al., 1998) and chronic illness (Sieh et al., 2012). Notably, Turner-Cobb et al (1998) and Sieh et al (2012) found that despite reporting greater daily hassles or perceived stress, children of parents with RA did not demonstrate higher levels of cortisol compared to children of healthy parents. The researchers of these studies (Chi et al., 2015; Turner-Cobb, Steptoe, Perry, Axford, et al., 1998; Slatcher et al., 2015) concluded that these findings may suggest that children of chronically ill parents (but not defined explicitly as young carers) may show physiological resilience, despite self-reported stress suggesting otherwise. This may be explained by a lower level of allostatic load than adult and elderly carers, given the relatively few years that young people have had to accumulate lifetime stress and develop chronically elevated cortisol levels compared to adult and elderly carers. Unlike elderly carers, who typically experience a decline in functioning as they age, young carers provide care whilst navigating phases of significant biopsychosocial development. This may potentially have both short and long-term impacts on the developing child's health trajectory across the lifespan.

There is a need to extend work in this area to identify and subsequently promote psychosocial factors that may provide protection against stress and contribute to psychophysiological resilience in young carers. This is turn may prevent psychophysiological disruption across the lifespan. An approach that focuses only on psychological resilience whilst neglecting physiological mechanisms, enables only part of the picture of resilience to be identified. Therefore, it is important to take a combined, biopsychosocial approach. An effective understanding of psychophysiological outcomes in young carers, and the pathways through which they are reached is necessary. If this understanding is gained, and protective factors are identified, they can be harnessed to promote resilience in young carers.

6.2.1 Contextualising this study within the wider research programme

This study builds upon the findings of both the systematic review and the photo elicitation study presented earlier in this thesis. Factors impacting adjustment identified within the systematic review and the key protective factors identified within the interview data provided a basis upon which to choose specific variables to measure within the current study.

The systematic review (chapter four) identified a number of commonly measured factors that contribute to both positive and negative adjustment in informal carers of all ages. These included problem focussed coping, emotion focussed coping, avoidant coping, cognitive coping strategies (such as acceptance and benefit finding) and social support (both tangible practical support and emotional support, from sources including family, friends and other carers). These factors identified in the systematic review were all described by participants in the interview study, thus confirming that these factors are relevant within the specific context of young carers, offering insight beyond that of solely adult and elderly carers. The interview study also found additional factors that young carers believed helped them to cope with their responsibilities and the stress of caregiving. These included seeking solitude, support from pets and inanimate objects, professional support, access to carer activities, being outdoors and utilising disability aids.

As a result, the measures selected for the current study were drawn from factors identified in the general carer literature, the literature surrounding coping and adjustment in carers of all ages and the direct, specific experiences of young carers explored in interviews, which provided context and relevance to those factors identified within the general carer literature. This study therefore builds upon the culmination of work conducted thus far in this programme of research.

6.2.2 Aims, objectives and hypotheses

6.2.2.1 Aims of the research

As the third and final part of a programme of research, this study aimed to extend current carer literature to assess the physiological impact of caring in a cross-sectional sample

of young carers, to provide a fuller understanding of the potential pathways to psychophysiological outcomes.

The aims of the study were to explore group differences between young carers and age matched non-carers, to establish the relationships between outcome variables and to identify psychosocial factors that may contribute to resilience, perceived stress and hair cortisol concentration.

6.2.2.2 Objectives

The study aims were achieved through the collection of data from two samples, young carers and age-gender matched non-carers for comparison. Data were collected in the form of questionnaires to assess perceived stress, psychological resilience and further psychosocial factors; and hair samples to assess hair cortisol concentration as a measure of physiological outcomes in the population of young carers.

6.2.2.3 Hypotheses

Hypotheses were developed on the basis of previous literature and findings of the systematic review and qualitative phase of the research.

6.2.2.3.1 Between group differences in perceived stress and hair cortisol concentration

Given the body of evidence that indicates that carers report greater perceived stress and demonstrate elevated cortisol levels compared to non-carers (Kiecolt-Glaser et al., 1987, 1996; Vedhara et al., 1999; Vitaliano et al., 1997). Hypothesis one was that:

> H1) Young carers would report greater perceived stress and demonstrate greater hair cortisol concentration than age matched non-carers.

6.2.2.3.2 Relationships between perceived stress, resilience and hair cortisol concentration

Further directional hypotheses were developed to explore the relationships between perceived stress, resilience and hair cortisol concentration. These hypotheses were developed on the basis of literature as discussed above and throughout the literature review (chapter two), and predicted that in both groups (young carers and matched non-carers):

> H2) There would be a positive association between perceived stress and hair cortisol concentration.
>
> H3) There would be a negative association between perceived stress and resilience.
>
> H4) There would be a negative association between resilience and hair cortisol concentration.

H5) Resilience would mediate the relationship between perceived stress and hair cortisol concentration.

6.2.2.3.3 Relationships between perceived stress, benefit-finding and hair cortisol concentration

Benefit finding was also explored as a potential mediating factor of the relationship between perceived stress and hair cortisol concentration on the basis that previous literature has identified a link between perceived stress/stress appraisal and benefit finding, and provided evidence of benefit finding mediating health outcomes in both adult and young carers (Cassidy, 2013; Cassidy et al., 2014). Hypotheses predicted that in both groups (young carers and matched non-carers):

H6) there would be a negative association between benefit finding and perceived stress

H7) there would be a negative association between benefit finding and hair cortisol concentration.

H8) that benefit finding would mediate the relationship between perceived stress and hair cortisol concentration.

6.2.2.3.4 Regression analyses

Hypotheses for regression analyses were developed on the basis of the limited previous literature and after conducting a correlation matrix between the independent and dependent variables (see appendix G). The correlation matrix was conducted to establish the initial relationships between variables due to a lack of previous literature with young carers. The correlation matrix enabled decisions to be made regarding which variables to enter into the regression models. The hypotheses predicted that in the combined sample (young carers and matched non-carers), when controlling for multiple deprivation:

H9) Caregiver status, frequency of avoidant coping, resilience and benefit finding would predict variance in perceived stress.

H10) Caregiver status, family support, benefit finding, perceived stress and social support would predict variance in resilience.

H11) Caregiver status, perceived stress, social support, resilience and benefit finding would predict variance in hair cortisol concentration.

H12) Social support would moderate the relationship between perceived stress and hair cortisol concentration.

6.3 Method

6.3.1 Participants and recruitment

Ethical approval for this study was granted by the University of Bath Social Sciences Research Ethics Committee (SSREC) on September 27th 2017. An opt-in recruitment method was adopted and various approaches were used for both young carers and age-gender matched non-carers as illustrated below in figures 6.1 and 6.2. In all instances, adverts invited young people aged 11 to 18 years old with hair of at least 2cm in length at the back of their head, to take part in a study involving the completion of questionnaires and the provision of a hair sample. Prospective participants with hair shorter than 2cm were unable to provide the required amount of hair for reliable assay analysis and were therefore excluded. The age range of 11 to 18 years was chosen based on research demonstrating that hair cortisol concentration reference ranges increase with age between 4 and 9 years of age and are more stable after this point (Noppe et al., 2014).

Posters were used to recruit both young carers and non-carers, and were placed on local notice boards, within schools and at sports centres and youth clubs. A digital version of the poster was published on Twitter, Facebook, Instagram and online parenting forums. Both versions of the poster invited young carers and non-carers to take part in the study. Schools were approached via email inviting young carers and non-carers to take part. Non-carers were also recruited via university staff who had children fitting the inclusion criteria to take part and were reached through an online staff notice board, physical notice boards and the distribution of flyers. Following this, snowball sampling occurred whereby these non-carers invited friends or family members to participate in the study either verbally or through distribution of flyers advertising the study.

In addition to posters, young carers were recruited via organisations such as carers' centres, charities and support services located in the South West of England and South Wales. Emails were sent to young carer leads or project managers explaining the study and inviting them to be involved. A follow up phone call was made a week after the email was sent and further information was given. Carers' organisations were given the option of holding an event whereby multiple young carers attended and the researcher visited them to collect data. Some carers centres chose this option whilst others provided details of the study for service users to contact the lead researcher and arrange a home visit. Thirty-nine carers centres were sent an initial email, 21 either responded to an email or were reachable via phone call and a total of six carers' centres were involved in the study by either enabling recruitment or hosting a data collection event.

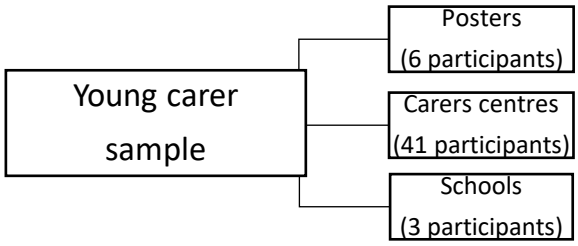

Figure 6.1 Number of young carers recruited via different recruitment sources

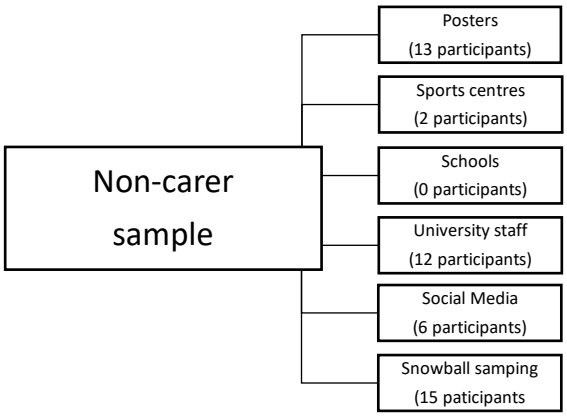

Figure 6.2 Number of age matched non-carers recruited via different recruitment sources

Ninety-eight participants took part in the present study, 50 young carers (31 female, 18 male, one non-binary) and 48 age and gender matched non-carers (30 female, 18 male). Four young carers and two non-carers did not wish to provide a hair sample at the time of data collection or had hair that was less than 1cm in length but completed the questionnaires in full; this data was included in the analysis. Young carers and non-carers were matched during recruitment on age and gender, and t-test analyses revealed no significant group differences in age (from this point 'non-carer' refers to age and gender matched non-carers). Detailed demographic information such as age, gender and social deprivation status are reported in the results section. The sample was predominantly white British (n = 63), with a further 19 participants identifying as Welsh, six identifying as Black British, four identifying as Indian, four identifying as Pakistani and two as Chinese.

6.3.2 Measures

6.3.2.1 Questionnaires

All participants were given a booklet consisting of questionnaires for them to complete. Participants were encouraged to complete the questionnaire alone, but in some instances required input from parents or caregivers to understand questions or retrieve specific details such as postcode. All measures are described in detail in chapter three (methodology) but are briefly described here in relation to the current study and participants.

Demographic information was requested including postcode (to calculate Multiple Deprivation Index), age, gender and ethnicity. Participants were asked to specify when they had last washed their hair, whether they used anti-dandruff shampoo, if their hair was currently dyed, bleached or permed, and finally if they had changed hair care products in the last three months. Hair related questions were asked to account for any outliers that may have arisen during data analysis, as factors such as hair cleanliness, treatments and products have in some instances been found to impact hair cortisol concentration (Hoffman, Karban, Benitez, Goodteacher, & Laudenslager, 2014; Dettenborn, Tietze, Kirschbaum, & Stalder, 2012; Gray et al., 2018; Stalder & Kirschbaum, 2012; Staufenbiel, Penninx, de Rijke, van den Akker, & van Rossum, 2015). Young carers were asked to provide details of their caregiving including who in their family they cared for, and what condition the family member/s had.

The Social Readjustment Rating Scale for teenagers (SRRS: Holmes & Rahe, 1967) was used to assess stressful life events in the past year of a teenagers life whereby participants answered 'yes' or 'no' to specific life events. The Holmes and Rahe (1967) weighting system was used to score each item (ranging from 26 to 100) based on how stressful it is deemed to be (e.g. parent starting work = 26, death of parent = 100). A total life events score was calculated with a possible maximum of 1716 (where a participant has experienced all events within the scale) and a minimum of zero (where a participant has experienced none of the events within the scale).

Assessment of coping strategies was via the KIDCOPE-11 questionnaire designed specifically for use in children and adolescents (Spirito et al., 1988). Participants were required to recall a stressful or challenging situation and respond to 11 items assessing the frequency and perceived efficacy of 10 coping strategies (distraction, social withdrawal, wishful thinking, self-criticism, blaming others, problem solving, emotional regulation, cognitive restructuring, social support and resignation). Frequency was rated 'not at all', 'sometimes', 'a lot of the time' or 'almost all the time' and efficacy was rated 'not at all helpful', 'a little helpful', 'somewhat helpful', 'pretty much helpful' or 'very much helpful'. Previous studies have sought to organise the coping strategies into specific domains of coping for analysis, and a previous study by Turner-Cobb et al, (1998) conducted a factor analysis and found that nine of the ten coping strategies loaded strongly onto either problem-focussed coping, emotion-focussed coping or avoidant coping. Emotional regulation did not load onto the three factors, however in the current study items in the KIDCOPE that assessed emotional regulation were added to the emotion-focussed category, as it was considered to be the most relevant of the three factors on the basis of previous coping literature. Mean scores for both frequency and perceived efficacy were calculated for each of the three factors of coping and used in analysis. The KIDCOPE had acceptable internal consistency, according to George and Malley's (2003) guidelines, with a Cronbach Alpha coefficient of α=.714 in the current study.

Perceived stress was measured using the Perceived Stress Scale-10 (PSS; Cohen, 1994) whereby participants were presented with items surrounding thoughts and feelings indicative of stress. Items were rated on a scale of zero (never) to four (very often) and a total score was calculated, with a possible maximum total score of 40 and a minimum of zero. The PSS-10 had good internal consistency (α= .884) in the current study.

The Child and Youth Resilience Measure-28 (CYRM-28; Ungar & Liebenberg, 2011) was used to measure resilience in participants, presenting them with 28 items related to different facets of resilience. Participants were required to rate the extent to which statements such as 'I have people to look up to' and 'I try to finish what I start' apply to them ranging from 'not at all' to 'a lot'. Items were rated on a scale from zero (not at all) to four (a lot). A final overall resilience score was calculated and the maximum possible total score was 112 and the minimum was zero. This particular scale was chosen on the basis that it measures resilience from three sources, the individual, the primary caregiver and the context. These domains feature factors that were demonstrated in the interviews conducted with young carers, and align with the categories within the socioecological model of resilience discussed in the literature review (Chapter two; 2.4.4) and found in the interview study; individual, community and society. The CYRM-28 had excellent internal consistency (α= .922) in the current study.

Benefit finding was measured using the Benefit Finding Scale for Children (BFSC; Phipps, Long, & Ogden, 2007) which, similarly to the KIDCOPE-11, required participants to recall a difficult or challenging situation and respond to ten items based on this experience. Items were rated on a scale from zero (not at all true) to four (very true of me). A total benefit finding score was calculated with a maximum possible score of 40 and a minimum of zero. The BFSC had excellent internal consistency (α= .905) in the current study.

Family support was measured using the Wills Family Support Inventory (WFSI; Willis, 1985) and required participants to rate 15 family related items on the extent to which they described them and their family. Items were rated on a scale from zero (not at all) to three (very much). Item three was reverse scored during coding before a total family support score was calculated, with a maximum possible score of 45 and a minimum possible score of zero. The WFSI had excellent internal consistency (α= .926) in the current study.

The Perceived Social Support from Friends scale (PSS-Fr; Procidano & Heller, 1983) was used to measure general social support in participants and featured 20 items which asked participants to rate whether statements were representative of them and their friends. Items were rated as zero (no and don't know) or one (yes). Items 3,4,14 and 18 were reverse coded before a total social support score was calculated with a maximum possible score of 20 and minimum of zero. The PSS-Fr scale had good internal consistency (α= .862) in the current study.

To determine the multiple deprivation index (MDI) for each participant, postcodes were entered into the government database whereby locations were ranked either in the 50% most or least deprived. Participants were given a score between 1 and 10, whereby 1 represented the

10% least deprived, and 10 represented the 10% most deprived. Scores ranged from three to 10 in the young carer sample (M = 3.84, SD = 1.77) and one to nine in the non-carer sample (M = 5.48, SD = 2.35). An independent samples t-test revealed that the difference in these mean scores was significant (t (96) = -3.89, p = <.001) with a medium magnitude of differences in means (mean difference = -1.64, 95% CI: -2.48 to -.80, Cohen's d = .78). Due to this significant group difference, MDI was controlled throughout analyses.

6.3.2.2 Hair cortisol sampling and assays

To measure hair cortisol concentration, one hair sample was collected from each participant who provided consent. Participants were asked to attend the data collection session with clean and dry hair, free from products such as dry shampoo or hair spray. A comb was used to part hair and clips allowed it to be clipped away from the back of the head, exposing the posterior vertex area of the scalp. Samples were taken from this area as it produces the lowest cortisol variability within and between individuals (Sauvé et al., 2007).

A lock of hair approximately 5mm in diameter was sectioned using a small elastic hair band. At this point, participants were given the option to see the section of hair either via a mirror or a photograph taken on a mobile phone, which was deleted immediately after viewing. If the participant verbally assented, the lock of hair was carefully cut in a single, straight cut, as close to the scalp as possible with professional hair cutting scissors. Once cut, the hair sample was placed onto a piece of aluminium foil, and without bending the sample, the foil was folded to hold the sample safely inside. Participant ID labels were placed onto the foil and samples were stored in a locked location, in a breathable container and a temperature and humidity controlled environment.

Following completion of data collection, samples were sent to Anglia Ruskin Biomarker Analysis Laboratory for analysis. Prior to analyses hair samples were prepared by washing them in 1ml of isopropanol, allowing external contaminants to be removed. Hair samples were left to dry in a clean air environment for 48 hours after which five ceramic balls were placed into the tube and the hair samples were ground into a very fine powder. Methanol (1.75ml) was then added to the samples, at which point they were incubated for 24 hours at room temperature whilst being shaken to extract the cortisol. The contents of the tube were then placed into a polypropylene tube. These tubes were centrifuged at 1500 RCF for five minutes, allowing the ceramic balls and mixture to be separate. The ceramic balls were removed and the tube was centrifuged at 3000 RCF for fifteen minutes to separate the ground hair and methanol. Clear methanol solution was extracted at the volume of 1.25ml and placed into a cryovial, then vacuum centrifuged at 37°C at 1700 RPM to remove the methanol. Following this, tubes were stored at -80°C before being thawed and reconstituted with 0.125ml of Salimetrics cortisol assay diluents. Samples were then assayed using standard Salimetrics cortisol assay protocol. Cortisol levels were expressed by picograms per milligram (pg/mg).

6.3.3 Procedure

Prospective participants (and parents where young people were under 16 years old) were given information sheets by the researcher, by post or via a third party (e.g. carer organisation staff). For those requiring the researcher to travel, a video of the researcher talking about the study was hosted online. Participants and their parents could ask questions in person, via email or by telephone at any time.

Participants met with the researcher in their own home, at the university research laboratory or at a carers' organisation event. In person, the hair sampling procedure was re-explained to ensure written consent was fully informed. Where parents were present and participants were under 16 years old, written parental consent was obtained. Where parents were not present (e.g. at carers organisation events), an online consent form, which could only be completed after watching the video, was completed.

Once consent had taken place, participants completed the questionnaires. Some participants requested the questionnaire to be posted in advance and completed it prior to meeting with the researcher. Participants were able to seek clarification about questions within the booklet at any time.

Next, the hair sample was taken using the procedure above. Each stage of the sampling was explained to the participants who were given two further opportunities to decline provision of a hair sample before the hair was cut. The sample was collected and stored as required before a verbal debrief was delivered. Participants were thanked and provided with a £5 'Love to Shop' voucher as reimbursement for their rime, which they signed to confirm they had received. Finally, where appropriate, participants were given flyers to give to friends who might be interested in study participation.

The duration of the study ranged from 30 to 60 minutes, depending on the speed of questionnaire completion and whether questions were asked. Participants were given an anonymous ID beginning with either YC (young carer) or MC (matched control) to ensure anonymity of data.

6.3.4 Data analysis plan

Initial descriptive statistics and correlation matrices between all variables were produced. Hypotheses were then tested using a range of inferential statistical procedures. Differences between groups in perceived stress and hair cortisol concentration were examined using independent samples t-tests. Pearson's correlations were conducted to explore relationships between perceived stress, resilience and hair cortisol concentration, and perceived stress, benefit finding and hair cortisol concentration, with a mediation analysis planned to assess whether benefit finding was a mediator of perceived stress and hair cortisol concentration.

Hierarchical Regression analyses were used to explore contributors to variance in the dependent (outcome) variables of resilience, perceived stress and hair cortisol concentration, whereby psychosocial measures were entered as independent (predictor) variables with multiple deprivation index entered as a covariate. Following regression analyses, a moderation analysis was planned, where the interaction between perceived stress and social support was conceptualised as a moderator in a hierarchical regression predicting variance in hair cortisol concentration, with multiple deprivation index as a co-variate.

6.4 Results

6.4.1 Data screening

The recommended data screening techniques of Tabachnick and Fidell (2012) and Field (2009) were used to screen the data prior to statistical analysis. A number of assumptions must be met before carrying out statistical analysis using techniques such as t-tests, correlations and regression.

Prior to conducting any analysis, data were screened for outliers via z scores and box plots. YC101 showed a z score for hair cortisol concentration that was outside the acceptable range of +/-3.29 and was shown as an extreme outlier on the boxplot for cortisol. Furthermore, this participant was an outlier on social support and family support variables. YC146 was shown to be an extreme outlier on the boxplot for cortisol and for scores on the KIDCOPE variables. Finally, MC134 was shown to be an extreme outlier on the boxplot for cortisol. As a result, these three cases were removed from the dataset and excluded from analysis.

In order to assess normal distribution, Q-Q plots and histograms were visually inspected and showed that all of the variables except hair cortisol concentration were normally distributed. The histogram for this variable indicated a positive skew. Upon further statistical assessment of normality for this variable, the means scores for skewness and kurtosis were outside the acceptable range of -2 to +2. Furthermore, the Kolmogorov-Smirnov test and Shapiro-Wilk test were both significant (<.001) indicating that the variable of hair cortisol concentration was not normally distributed. In order to ensure the assumption of normality was met for the planned data analysis, the variable was transformed using a Log 10 transformation. Following this transformation, re-assessment of the indicators of normality showed that hair cortisol concentration was normally distributed.

Additional assumptions for correlation (linearity and homoscedasticity) were assessed via scatterplots and showed no issues for any variables. For regression, the assumptions of normality, linearity, homoscedasticity and independence of residuals were assessed via post-hoc analysis of Normal Probability Plots (P-P) and scatterplots of residuals and showed no issues with these assumptions. For certainty, further outliers were checked by inspecting Mahalanobis distances, none of which were greater than the critical chi-square value calculated. For the t-tests, in addition to assessment of outliers, independence of observations and normality, the

assumption of homogeneity of variance was addressed post-hoc through observation of Levene's Test and the appropriate finding is reported based on the significance of this test.

6.4.2 Descriptive statistics

Following the removal of extreme outliers, data from 95 participants were analysed, with 89 of these providing a hair sample. Of these participants 48 (50.5%) were young carers and 47 (49.5%) were non-carers.

Young carers ranged from 11 to 17 years old (M = 13.43 , SD = 1.56) and 30 (62.5%) identified as female, 17 (35.4%) identified as male and one (2.1%) identified as non-binary. The mean MDI score in young carers was 3.77 (SD = 1.69).

Non-carers ranged from 11 to 18 years old (M =13.53, SD = 1.81) and 29 (61.7%) identified as female and 18 (38.3%) identified as male. The mean MDI score in non-carers was 5.53 (SD = 2.34).

The sample as a whole included 59 females, 35 males and one non-binary individual with a mean age of 13.48 years (SD – 1.68) and mean MDI score of 4.64 (SD = 2.21).

With regard to caregiving context, of the 48 young carers, 37 were caring for one person, nine were caring for two people and two were caring for three people. Twenty-nine young carers provided care to their mothers, seven to their fathers, 19 to their brothers, 14 to their sisters, four to their grandparents and one listed 'other' but did not state who this was. The conditions that family members had included both mental, physical, acute and chronic health conditions, examples of which are shown in table 6.1 (the frequencies of each condition can be found in Appendix H).

The means and standard deviations for each of the questionnaires and hair cortisol concentration are presented below in table 6.2 for the young carer sample, non-carer sample and the sample as a whole. Notably, the mean cortisol concentration values fall within the range identified in healthy children and adolescents by Noppe et al (2014) and Prado-Gasco et al (2019).

Table 6.1

Conditions of family members cared for by young carers

Health condition
Mental health & behavioural conditions (Bipolar disorder, Unipolar depression, Anxiety, Autism, ADHD, Asperger Syndrome, Undefined mental health condition)
Digestive conditions (Coeliac disease, irritable bowel syndrome, Crohn's disease)
Cardiovascular conditions (Hypertension, Angina, Heart Attack, Heart Disease, Postural orthostatic Tachycardia Syndrome)
Endocrine/Metabolic conditions (Type 2 diabetes, Hashmito's, Autoimmune disease)

Ear, Nose and Throat conditions (hearing impairment, deafness, sleep apnoea)
Eye conditions (visual impairment)
Gynaecological conditions (Endometriosis, fibroids)
Musculoskeletal conditions (arthritis, curvature of the spine, back pain, knee pain, sciatica, hypermobility, carpal tunnel, spondylitis, general mobility issues)
Neurological conditions (Cerebral palsy, Alzheimer's/Dementia, Epilepsy, Motor Neurone disease, multiple sclerosis, narcolepsy, fibromyalgia, learning disability, dyslexia, dyspraxia)
Respiratory conditions (Asthma, cystic fibrosis)
Skin conditions (Eczema)
Chromosomal conditions (Down's Syndrome, Ehlers-Danlos syndromes, Rett syndrome)
Other conditions (Chronic Fatigue Syndrome, Complex Regional Pain Syndrome, secondary breast cancer, undefined physical disability, undefined chronic pain)

Note. Conditions categorised in accordance with NICE guidelines and categorisations.

Table 6.2

Means, standard deviations (SD), Minimum (Min) and Maximum (Max) scores for all questionnaire measures and hair cortisol concentration values for young carers, non-carers and the whole sample. The possible range is included after the name of each variable in brackets (min-max).

	Young carer sample			Non-carer sample			Whole sample		
	Mean (SD)	Min	Max	Mean (SD)	Min	Max	Mean (SD)	Min	Max
Cortisol concentration (pg/mg)	7.76 (4.67)	2.04	27.59	9.29 (5.97)	2.48	30.32	8.53 (5.39)	2.04	30.32
Multiple Deprivation *(0-10)*	3.77 (1.69)	3.00	10.00	5.53 (2.34)	1.00	9.00	4.64 (2.21)	1.00	10.00
Life events *(0-1716)*	222.68 (154.79)	0.00	785.00	113.44 (96.39)	0.00	361.00	168.64 (139.80)	0.00	785.00
Coping									
Problem focussed frequency *(0-12)*	3.93 (1.93)	0.00	8.00	4.34 (2.12)	0.00	9.00	4.15 (2.03)	0.00	9.00
Problem focussed efficacy *(0-12)*	5.32 (3.04)	0.00	11.00	6.45 (2.93)	0.00	12.00	5.91 (3.02)	0.00	12.00
Emotion focussed frequency *(0-12)*	6.37 (1.80)	3.00	10.00	5.02 (2.40)	0.00	10.00	5.65 (2.24)	0.00	10.00
Emotion focussed efficacy *(0-12)*	5.83 (3.10)	0.00	12.00	4.84 (2.49)	0.00	9.00	5.32 (2.83)	0.00	12.00
Avoidant coping frequency *(0-12)*	5.00 (1.85)	2.00	9.00	3.86 (1.98)	0.00	7.00	4.41 (1.99)	0.00	9.00
Avoidant coping efficacy *(0-12)*	4.00 (2.48)	0.00	11.00	3.54 (1.61)	0.00	7.00	3.76 (2.08)	0.00	11.00
Perceived Stress *(0-40)*	21.68 (7.68)	6.00	36.00	15.61 (7.26)	1.00	31.00	18.68 (8.04)	1.00	36.00
Resilience *(0-112)*	70.35 (19.15)	34.00	102.00	80.57 (15.06)	42.00	109.00	75.41 (17.90)	34.00	109.00
Benefit finding *(0-40)*	23.72 (10.91)	0.00	40.00	22.42 (9.60)	3.00	38.00	23.04 (10.21)	0.00	40.00
Family support *(0-45)*	32.26 (9.38)	11.00	45.00	37.68 (6.60)	13.00	45.00	35.00 (8.50)	11.00	45.00
Social support *(0-20)*	10.91 (5.46)	0.00	19.00	13.28 (4.17)	2.00	19.00	12.09 (4.97)	0.00	19.00

6.4.3 Inferential statistics

6.4.3.1 Between group differences in perceived stress and hair cortisol concentration

The T-test comparison of perceived stress found a significant difference in scores between young carers (M= 21.68, SD = 7.68) and non-carers (M = 15.61, SD =7.27; t (93) = 3.96, p = <.001). The magnitude of differences in means (mean difference =6.07, 95% CI: 3.02 to 9.11) was large (Cohen's d = 0.81). Indicating that, as hypothesised, young carers report greater perceived stress than controls.

The T-test comparison of hair cortisol concentration (Lg10 transformed) found no significant difference in hair cortisol concentration levels in young carers (M = .832, SD = .22) compared to non-carers (M = .894, SD = .23; t (87) = -1.22, p = >.05), thus not supporting hypothesis 1.

6.4.3.2 Relationships between perceived stress, resilience and hair cortisol concentration

Partial correlations were run between variables separately for each group (young carers and non-carers) to identify relationships between perceived stress, resilience and hair cortisol concentration. In all correlations, multiple deprivation was controlled for.

6.4.3.2.1 Young carers

The correlation analyses between hair cortisol concentration, perceived stress and resilience for the young carer group are presented in table 6.3 below. Observation of the zero order correlations for hair cortisol concentration and perceived stress (r = .306), hair cortisol concentration and resilience (r = .269) and resilience and perceived stress (r = .532) suggested that controlling for multiple deprivation had little impact on the strength or significance of the relationships between variables.

Table 6.3

Correlations between perceived stress, hair cortisol concentration and resilience in the young carer sample

	Perceived Stress	Hair Cortisol Concentration	Resilience
Perceived Stress	----		
Hair Cortisol Concentration	.313*	----	
Resilience	-.493***	.276	----

Note: * = p <.05, *** = p <.001.

Due to a non-significant relationship between hair cortisol concentration and resilience, the requirements for mediation were not met. Therefore mediation analysis assessing the effect of

resilience on the relationship between perceived stress and hair cortisol concentration was not conducted with the young carer sample. Therefore hypothesis four was not tested.

6.4.3.2.2 Non-carers

The correlation analyses between hair cortisol concentration, perceived stress and resilience for the non-carer group are presented in table 6.4 below.

Table 6.4

Correlations between perceived stress, hair cortisol concentration and resilience in the non-carer sample

	Perceived Stress	Hair Cortisol Concentration	Resilience
Perceived Stress	----		
Hair Cortisol Concentration	-.014	----	
Resilience	-.422**	-.191	----

Note: ** = p <.01.

Observation of the zero order correlations for hair cortisol concentration and perceived stress (r = -.000), hair cortisol concentration and resilience (r = -.186) and resilience and perceived stress (r = -.423) suggested that controlling for multiple deprivation had little impact on the strength or significant of the relationships between variables. Due to non-significant relationships between hair cortisol concentration and resilience, and hair cortisol concentration and perceived stress, the requirements for mediation analysis were not met. Therefore mediation was not run with the non-carer sample and hypothesis four was not tested. Combined with the young carer group correlations, these findings lead to the rejection of hypotheses two and four, and the acceptance of hypothesis three.

6.4.3.3 Relationships between perceived stress, benefit-finding and hair cortisol concentration

Partial correlations were run between variables separately for each group (young carers and non-carers) to identify relationships between perceived stress, benefit finding and hair cortisol concentration. In all correlations, multiple deprivation was controlled for.

6.4.3.3.1 Young carers

The correlation analyses between hair cortisol concentration, perceived stress and benefit-finding for the young carer group are presented in table 6.5 below. Observation of the zero order correlations for hair cortisol concentration and perceived stress (r = .306), hair cortisol concentration and benefit-finding (r = .070) and benefit finding and perceived stress (r =

-.456) suggested that controlling for multiple deprivation had little impact on the strength or significant of the relationships between variables.

Table 6.5

Correlations between perceived stress, hair cortisol concentration and benefit finding in the young carer sample

	Perceived Stress	Hair Cortisol Concentration	Benefit-finding
Perceived Stress	----		
Hair Cortisol Concentration	.313*	----	
Benefit-finding	-.477***	.008	----

Note: * = p<.05, *** = p<.001

Due to a non-significant relationship between hair cortisol concentration and benefit finding, mediation analysis assessing the effect of benefit finding on the relationship between perceived stress and hair cortisol concentration was not conducted with the young carer sample. Therefore hypothesis eight was not tested.

6.4.3.3.2 Non-carers

The correlation analyses between hair cortisol concentration, perceived stress and benefit-finding for the non-carer group are presented in table 6.6 below. Observation of the zero order correlations for hair cortisol concentration and perceived stress (r = -.000), hair cortisol concentration and benefit-finding (r = -.184) and benefit finding and perceived stress (r = -.185) suggested that controlling for multiple deprivation had little impact on the strength or significance of the relationships between variables.

Table 6.6

Correlations between perceived stress, hair cortisol concentration and benefit finding in the non-carer sample

	Perceived Stress	Hair Cortisol Concentration	Benefit-finding
Perceived Stress	----		
Hair Cortisol Concentration	-.014	----	
Benefit-finding	-.178	-.184	----

Due to non-significant relationships between all variables, mediation analysis assessing the effect of benefit finding on the relationship between perceived stress and hair cortisol concentration was not conducted with the non-carer sample. Therefore hypothesis eight was not tested. Combined with the young carer correlations, these findings lead to the rejection of hypotheses six and seven.

6.4.3.4 Regression analyses

Hierarchical regression allowed for deprivation to be entered as a co-variate and for caregiver status to be entered in order to evaluate the effect of this factor on the dependent variables. Variables were entered on the basis of previous literature support and those predicted to be most impactful on the dependent variable as established via correlation matrices of all variables.

6.4.3.4.1 Perceived stress as the dependent variable

A hierarchical multiple regression revealed that when entered in step 1, multiple deprivation did not show a significant contribution to the prediction of perceived stress. After entry of caregiver status, resilience, avoidant coping frequency and benefit finding at Step 2, the total variance explained by the model as a whole was 58.5%. The four measures explained an additional 56.9% of the variance in perceived stress after controlling for multiple deprivation. In the final model, three of the measures were statistically significant, with avoidant coping frequency recording a higher beta value (beta = .54, p <.001), than resilience (beta = -.27, p <.01) and caregiving status (beta = -.17, p <.05). The full regression model, including non-significant contributors to the overall model, is presented in table 6.7 below. These findings lead to the partial acceptance of hypothesis nine, as all variables except benefit finding contribute to variance in perceived stress.

Table 6.7

Regression model for perceived stress

	R	R_2	R_2 change	B	SE	β	t
Step 1	.128	.016					
Multiple Deprivation				-.46	.39	-.13	-1.19
Step 2	.765	.585***	.569***				
Multiple Deprivation				.12	.29	.03	.42
Caregiver Status				-2.70	1.35	-.17*	-1.00
Resilience				-.12	.04	-.27**	-2.74
Avoidant coping (frequency)				8.43	1.23	.54***	6.84
Benefit finding				-.10	.07	-.13	-1.37

Note. * = p<.05, **= p<.01, ***= p<.001

6.4.3.4.2 Resilience as the dependent variable

A hierarchical multiple regression revealed that when entered in step 1, multiple deprivation did not show a significant contribution to the prediction of perceived stress.

After entry of caregiver status, family support, social support, benefit finding and perceived stress at Step 2, the total variance explained by the model as a whole was 74.2%. The five measures explained an additional 74.1% of the variance in self-reported resilience scores after controlling for multiple deprivation. In the final model, four of the variables were statistically significant predictors of self-reported resilience scores, with family support recording the highest beta value (beta = .46, p <.001) than benefit finding (beta = .25, p <.001), social support (beta = .26, p <.001) and perceived stress (beta = -.17, p <.01). The full model, including non-significant contributors, is presented below in table 6.8. These findings enable hypothesis ten to be partially accepted, as all variables except caregiver status

Table 6.8

Regression model for resilience

	R	R_2	R_2 change	B	SE	β	t
Step 1	.018	.000					
Multiple Deprivation				.14	.88	.02	.16
Step 2	.861	.742	.741***				
Multiple Deprivation				-.33	.51	-.04	-.64
Caregiver Status				1.63	2.46	.05	.66
Family Support				.98	.15	.46***	6.45
Social Support				.94	.24	.26***	3.92
Benefit finding				.44	.12	.25***	3.70
Perceived Stress				-.37	.16	-.17*	-2.39

Note. * = p<.05, ***= p<.001

6.4.3.4.3 Hair cortisol concentration as the dependent variable

A hierarchical multiple regression revealed that when entered in step 1, multiple deprivation did not demonstrate any significant contribution to the prediction of hair cortisol concentration levels. Furthermore, after entry of caregiver status, perceived stress, social support, resilience and benefit finding in Step 2, the model continued to demonstrate no significant contribution to the prediction of hair cortisol concentration levels. The full model is presented below in table 6.9. These findings lead to the rejection of hypothesis 11 as none of the variables account for variance in hair cortisol concentration.

Table 6.9

Regression model for hair cortisol concentration

	R	R_2	R_2 change	B	SE	β	t
Step 1	.147	.022					
Multiple Deprivation				.02	.01	.15	1.40
Step 2	.234	.055	.033				
Multiple Deprivation				.02	.02	.17	1.50
Caregiver Status				-.02	.08	-.03	-.23
Perceived stress				-8.9	.01	-.00	-.02
Social Support				-.01	.01	-.19	-1.48
Resilience				.00	.00	.04	.22
Benefit finding				.00	.00	-.01	-.10

6.4.3.4.4 The impact of the relationship between perceived stress and social support

Based on literature supporting the role of social support as a buffer against the physiological impacts of stress, and the identification of social support as having a small but significant correlation with perceived stress in the correlation matrices conducted prior to analysis, a moderation analysis was conducted. Variables were centred prior to analysis and an interaction variable was computed. As before, deprivation was entered into the regression model in Step 1, and did not demonstrate any significant contribution to the prediction of hair cortisol concentration levels. After the entry of caregiver status, perceived stress, social support and the interaction variable in step 2, the model continued to demonstrate no significant contribution to the prediction of hair cortisol concentration levels. These findings are presented below in table 6.10 and lead to the rejection of hypothesis 12.

Table 6.10

Moderation model for hair cortisol concentration

	R	R_2	R_2 change	B	SE	β	t
Step 1	.147	.022					
Multiple Deprivation				.02	.01	.15	1.40
Step 2	.235	.055	.034				
Multiple Deprivation				.02	.02	.18	1.60
Caregiver Status				-.02	.07	-.03	-.23
Social Support				-.05	.03	-.18	-1.64
Perceived Stress				.00	.03	-.02	-.14
Perceived stress x Social Support				.01	.03	.03	.28

6.5 Discussion

The main findings will now be summarised and the strengths and limitations of this study will be discussed before conclusions are drawn.

6.5.1 Group differences

Findings from the current study mean that hypothesis one (young carers will report greater perceived stress and demonstrate greater hair cortisol concentration than non-carers) is partially accepted. T-test analyses found that although young carers reported significantly greater perceived stress than non-carers, they did not demonstrate greater hair cortisol concentration.

Given the demands placed upon young carers, it is unsurprising that this population report greater perceived stress than peers of a similar age who do not provide care to a family member. This finding is in line with previous literature that demonstrates that young carers reported greater perceived stress than non-carer controls, as determined in studies reviewed by Pinquart and Sörensen (2003). Furthermore, greater perceived stress is typically associated with greater cortisol in an elderly caregiving population (Davis & Cowen, 2001; Dich et al., 2015; Kim & Knight, 2008; Ruiz-Robledillo & Moya-Albiol, 2013) and therefore the current study predicted that young carers would demonstrate greater hair cortisol concentration than non-carers, however this was not found to be the case. As previously described, research findings surrounding stress and physiological outcomes in adult carers and young people are mixed, with literature suggesting that the elevation of cortisol levels in relation to carer stress is less pronounced as the age of the carer decreases (Vedhara et al., 2002). Furthermore, literature surrounding children living with parental illness (but not formerly classified as young carers) found that despite reporting greater stress, and daily hassles, than controls, child and adolescent populations did not show greater cortisol concentration (Chi et al., 2015; Turner-Cobb, Steptoe, Perry, Axford, et al., 1998; Sieh et al., 2012; Slatcher et al., 2015). The results of the current study are in line with and supportive of these findings, and warrant further investigation to determine whether young people are demonstrating psychophysiological resilience.

The observed power of the t-test performed to compare perceived stress scores was 93.3%, indicating that this finding is unlikely to be due to a type 1 or type 2 error. On the other hand, the observed power of the t-test performed to compare groups on their hair cortisol concentration, was only 21.7%. It is possible that the findings of this test are due to a type 2 error. A priori power analysis using G*Power determined that in order to achieve a power of 0.8 and a medium effect size, a sample size of 51 participants per group was required. Unfortunately, due to recruitment limitations, and the exclusion of outliers, this sample size was not achieved, with the total participants for the young carer and non-carer groups totalling 44

and 45 respectively for the hair cortisol concentration t-test. Sample size will be discussed in the context of limitations later in this chapter.

6.5.2 Relationships between perceived stress, hair cortisol concentration and resilience

As hypothesised there was a positive association between perceived stress and hair cortisol concentration, but only in the young carer sample. This association between cortisol levels and perceived stress is reflective of the general stress literature, but also the literature that has explored this relationship in adult and elderly carers. Due to the lack of research exploring hair cortisol levels in carers, it is not possible to determine whether the strength of the relationship between perceived stress and hair cortisol follows a similar pattern as salivary cortisol in carers, whereby as age decreases, the impact of perceived stress on cortisol levels is less pronounced (Vedhara et al., 2002).

As predicted, a significant negative association between perceived stress and resilience was found, whereby greater scores on resilience were associated with lower scores on perceived stress, in both the young carer and the non-carer samples. This supports previous research identifying a negative association between resilience and perceived stress in adult cancer carers (Cassidy, 2013) and suggests that resilience may impact the level of stress an individual perceives themselves to be experiencing, whereby those with greater resilience report less perceived stress. Regression analyses were conducted to explore the contribution of perceived stress to resilience and vice versa, along with additional factors that were predicted to account for variance in these variables.

It was predicted, in line with previous literature, that there would be a negative relationship between resilience and hair cortisol concentration, whereby greater resilience would be associated with lower hair cortisol concentration levels. This was because previous literature had demonstrated a relationship between resilience and salivary cortisol levels in a carer population (Ruiz-Robledillo et al., 2014). The current study did not find a significant association between the variables of resilience and hair cortisol and therefore did not accept the hypothesis nor does it support previous research.

Within the data analysis plan, it was predicted that if the relationships tested above were found to exist and be significant, then resilience would mediate the relationship between perceived stress and cortisol, whereby resilience was anticipated to impact the physiological impact of perceived stress, and thus tempering the typical cortisol response to chronic stress observed in adult and elderly carers (Davis & Cowen, 2001; Kim & Knight, 2008). It was not possible to conduct a mediation analysis as the underlying requirements (correlations between all variables) had not been met.

6.5.3 Relationships between perceived stress, hair cortisol concentration and benefit finding

On the basis of previous literature it was predicted that relationships would exist between the variables of perceived stress, hair cortisol concentration and benefit finding, and that benefit finding would mediate the relationship between perceived stress and hair cortisol concentration in both groups. The association between perceived stress and hair cortisol concentration has been discussed in the previous section.

It was hypothesised that there would be a significant negative association between benefit finding and perceived stress. This was found to be true, but only in the young carer sample whereby greater scores on perceived stress were associated with lower scores on benefit finding. This supports previous literature that has found a significant negative association between benefit finding and stress appraisal in both adult cancer carers and young carers (Cassidy, 2013; Cassidy et al., 2014).

It was also predicted that there would be a negative association between benefit finding and hair cortisol concentration. Though research surrounding benefit finding and physical health outcomes in carers is sparse, literature in other populations such as women receiving treatment for early stage breast cancer (Cruess et al., 2000) and HIV-positive individuals (Carrico et al., 2006) have found that those reporting greater benefit finding demonstrate improved physiological outcomes such as reduced serum cortisol levels and decreased 24-hour cortisol output. This literature suggests that those seeking benefits in stressful experiences may show positive and adaptive physiological health outcomes (Bower, Low, Moskowitz, Sepah, & Epel, 2008), however this was not found to be the case in the current study, with no significant association identified between benefit finding and hair cortisol concentration.

The data analysis plan included a mediation analysis to explore whether benefit finding mediated the relationship between perceived stress and hair cortisol concentration, whereby benefit finding was anticipated to reduce the impact of perceived stress on hair cortisol concentration. This was based upon previous literature that has identified that benefit finding had a mediating effect on the impact of caregiving in young carers (Cassidy et al., 2014). Given that the underlying requirements for mediation analysis were not met (correlations between all variables), mediation was not run.

6.5.4 Factors impacting perceived stress, hair cortisol concentration and resilience

Regression analyses were conducted to explore the impact of psychosocial factors on the variance of three outcome variables, perceived stress, resilience and hair cortisol concentration.

Analyses identified that caregiver status, resilience and avoidant coping were all predictors of the variance within perceived stress scores. This is in line with previous literature that has found that carers report greater perceived stress than non-carers (Pinquart & Sörensen, 2003). Avoidant coping has been demonstrated to have a negative impact on carer adjustment in

general, with Mausbach et al (2013) reporting that carers using greater negative coping strategies such as avoidance report poorer psychosocial outcomes and adjustment, but also specifically in relation to perceived stress, as this regression analyses has demonstrated. The overall model accounted for 58.5% of variance in perceived stress scores, therefore although some factors were identified as contributing to this variance, over 40% of variance was not accounted for, suggesting other factors may be at play within perceived stress variance. Indeed, factors such as self-efficacy, appraisal of the carer role, perceived control, neuroticism and characteristics of the individual receiving care (such as aggression) have been associated with perceived stress in a carer population (Dias et al., 2015; Wilks, Little, Gough, & Spurlock, 2011; Zhang et al., 2014). Due to a lack of evidence showing these factors are significant in a young carer population within the literature, but also within the systematic review and qualitative analysis of the current programme of research, these factors were not measured in the current study. Future research may seek to explore additional factors that may be contributing to variance in hair cortisol concentration by recruiting a larger sample, enabling more variables to be included in the regression model.

A second regression analysis found that family support, social support, benefit finding and perceived stress were predictors of the variance within resilience scores of participants. Caregiver status however, did not predict any variance in resilience scores of participants. These factors support previous literature which has identified that social support contributes to resilience in adult and elderly carer populations (Dias et al., 2015; Ruiz-Robledillo et al., 2014; Wilks & Croom, 2008) and also in children of parents with mental illness (Fraser & Pakenham, 2009). Benefit finding has been positively associated with resilience in female cancer carers (Cassidy, 2013) and connected to resilience in the context of predicting variance of positive health in young carers and mediating the impact of caregiving (Cassidy et al., 2014). The current research provides further support for benefit finding in the context of young carers, specifically finding that it contributes to variance in resilience. Finally, lower levels of perceived stress were found to account for greater scores on resilience across the sample, and as highlighted above, the impact of perceived stress on resilience (and vice versa) has been established. The overall model accounted for 74.1% of the variance in resilience, therefore indicating that, as with the regression for perceived stress, other factors, not included in the analysis may have contributed to the variance in these scores and a larger sample would have allowed for additional variables to be assessed within the model.

A final regression model was conducted to ascertain factors influencing hair cortisol concentration, and neither the model as a whole, nor any of the individual independent variables were found to be significant predictors of the variance of hair cortisol concentration. This is not in line with predictions based on the existence of previous literature mostly utilising salivary cortisol, which demonstrates factors such as social support, benefit finding and perceived stress

have an impact on cortisol levels in carer populations (Kim & Knight, 2008; Kneebone & Martin, 2003).

Given the evidence to suggest that social support can act as a buffer of the physiological impact of perceived stress (Cosley, McCoy, Saslow, & Epel, 2010; Lovell, Moss, & Wetherell, 2012b; Turner-Cobb, Sephton, Koopman, Blake-Mortimer, & Spiegel, 2000), a moderation analysis was conducted to determine whether the interaction between perceived stress and social support was a moderator of hair cortisol concentration. Again, the overall regression model which included this interaction, and the individual independent variables within the model were non-significant. Due to the removal of outliers, and six participants who did not provide hair samples for analysis, the overall sample size for this regression was 84, therefore it is likely that the regression analysis was not sufficiently powered to detect effects. As discussed above, a larger sample size would allow for additional factors that have been associated with cortisol concentration (measured via plasma and saliva) to be measured, alongside exploratory factors that may be hypothesised to contribute to hair cortisol concentration levels. Finally, as noted by Prado-Gasco et al (2019) stress is complex with impacts that are widespread through various systems including cognitive, behavioural, emotional and physiological. Hair cortisol concentration is limited in that it can only capture HPA axis activity, and thus reflect only one component of the overall stress response and the biopsychosocial model of stress and resilience. Furthermore, measures such as the PSS-10 are based on an individual's subjective assessment of their stress and thus assesses only the cognitive aspect, and measures such as the CYRM, social support and benefit finding rely on self-report measures. The absence of a significant affect between any of the independent variables and hair cortisol concentration or the other dependent variables within the regression analyses may be due to additional factors impacting the variance of this variable that were not captured within the measures used for this study such as self-efficacy, appraisal of the carer role and perceived control as described above.

In all the regression analyses discussed above, compromises were necessary to ensure that an appropriate number of variables were included in the regression models, given the limited sample size. A larger sample would have allowed for further variables, both those with support in the literature and those that are more exploratory, to be included in the final regression models.

6.5.5 Strengths and limitations

There are a number of strengths and limitations of this study that warrant discussion and mainly consider the study design, the use of hair samples, questionnaire measures and finally the sample with regard to size and diversity.

6.5.5.1 Study design

The systematic review identified that the majority of carer research was cross-sectional, meaning that predictions and conclusions surrounding causation and the long term impacts of caregiving were not possible. As the physical impacts of caregiving can develop over time, a cross-sectional design is often not sufficient to identify these impacts and therefore longitudinal research is recommended (Kim & Knight, 2008). Chronic stress is long-term and enduring, in particular, the stressor of caregiving is characterised by fluctuations in levels of responsibility and perceived stress. A period of remission may entail less responsibility as conditions and symptoms are managed, or more responsibility if the individual receiving care is within the family home. In contrast, a relapse may entail less responsibility if the individual is cared for within a hospital, but may cause greater distress and disruption if hospital visits are required or prognoses are uncertain. This indicates the unique and fluctuating nature of long-term caregiving and thus the requirement for longitudinal research which may be able to capture these variabilities, the nuances and the situational factors that exist within a period of caregiving.

Given the limited literature in the area of psychophysiological outcomes in young carers, conducting an exploratory and cross-sectional study was deemed appropriate. The findings of the study were intended to provide a basis for future, longitudinal research which can explore the mechanisms of chronic stress within a youth caregiving population in greater depth. Hair cortisol concentration was chosen as a physiological measure as it reflects chronic stress unlike methods such as saliva, blood and urine which typically capture acute stress reactions and when used to assess long-term cortisol profiles often require increased burden and discomfort for participants and greater cost for research (Sauvé et al., 2007). Hair samples of 3cm in length (taken from the posterior vertex) typically measure the total activity of the HPA over the preceding three months, and hair cortisol concentration can be reliably assessed up to 6cm at which point a 'leeching effect' of cortisol occurs and concentration varies considerably (Wright, Hickman, & Laudenslager, 2015). Therefore, though this was a cross-sectional study design, hair cortisol concentration offered a retrospective proxy measure of total HPA activity and provided data about this activity prior to recruitment and collection of the hair sample (Wright, Hickman & Laudenslager, 2015), something that saliva, blood or urine samples would not have been able to obtain. The analysis of a single 3cm segment of hair was chosen on the basis of financial resources, however it is possible for hair samples to be analysed in 1cm segments, with each centimetre representing a month of cortisol production. Analysing samples in this way would allow for a more in depth view of cortisol concentration in the months prior to data collection, however it is arguable how useful this data might be without psychometric data alongside each month of cortisol production.

The final strength surrounding the design of the study was that it utilised a novel method during the recruitment stage whereby an informational video was provided in addition to written information that featured on the information sheet. This video was created to ensure

maximum accessibility, for example parents may have had conditions that limited their ability to concentrate, read or write. By including the information in video format, not only did parents and prospective participants have the opportunity to become familiar with the researcher, they were also able to access the information easily from any location and device with an internet connection and sign the consent form electronically. A number of participants provided informal feedback on the use of the video and described instances where they had previously been invited to participate in research but had felt nervous or reluctant to allow the researcher into their lives. The video provided an initial introduction to the researcher beyond a telephone call, email or information sheet and helped to put families at ease during the recruitment stage.

6.5.5.2 Hair cortisol concentration as a biomarker of stress

Whilst studies have measured physiological factors such as stress biomarkers in young people with parental illness (Chi et al., 2015; Turner-Cobb, Steptoe, Perry, Axford, et al., 1998; Sieh et al., 2012; Slatcher et al., 2015), the current study is the first to measure psychosocial factors alongside a physiological stress biomarker for the first time in a population explicitly defined as young carers. Of particular importance is the study's use of the measure of cortisol via hair samples, which though gaining popularity in the general adult stress literature, has rarely been used in an adult and elderly carer context (Chen et al., 2015; Stalder et al., 2014) and to date, has not been used with young carers. A number of methodological strengths regarding hair samples are noted. Using hair samples as a means to assess cortisol concentration within both young carers and non-carers was acceptable for over 94% of the participants who took part in this research, thus demonstrating that hair samples are an appropriate and acceptable method for assessing cortisol concentration in these populations. Of the six individuals who did not provide a hair sample, four were of African American descent. Although two participants with Afro hair did provide hair samples, four declined to do so, understandably due to complex hairstyles they did not wish to make their hair loose in order to provide the sample. Therefore, though hair samples were acceptable to the majority of young people, they were less so for this particular minority group. This is an important consideration with regards to inclusivity and representation within the sample. Future research may seek to consult with ethnic minority groups to establish whether this method is appropriate, whether steps can be taken to overcome issues faced or whether an alternative method needs to be utilised for those who do not feel comfortable providing a hair sample.

With regard to hair samples, the level of participant adherence required when collecting saliva samples was not necessary in this method. There are restrictions around consuming food and liquids before providing a saliva sample, and participants must adhere to strict instructions in order to not invalidate salivary samples. This is not the case for hair samples. Although participants are required to attend data collection with clean and dry hair, the precise sampling of hair is conducted by the researcher, meaning that the location and weight of the hair sample

can be more easily controlled, unlike with saliva samples which are vulnerable to more variance and contributing factors.

Despite the strengths of the hair sampling method, the lack of a multiple-biomarker approach is a limitation. As the current study was exploratory in nature a single biomarker of stress was used. Cortisol was chosen due to its reliability and strong evidence base with regard to its role within the context of chronic stress (Hellhammer et al., 2009). Measuring cortisol in isolation can provide information about sympathetic nervous system activity, in particular within the HPA axis. However, due to the absence of additional neuroendocrine or immunological markers associated with the overall stress response and specifically the parasympathetic nervous system, a full picture of the impact of chronic stress cannot be developed. For example, a number of studies have measured levels of DHEA alongside cortisol in order to produce a cortisol:DHEA ratio which can be used to assess the overall functioning of the HPA axis in individuals, with a higher ratio typically reported in those under chronic stress (Jeckel et al., 2009). Furthermore, inclusion of a biomarker such as salivary alpha amylase, which has been considered to represent activity within the SAM system, would allow for the different systems within the stress response to be assessed and evaluated within the context of chronic stress (Wolf, Nicholls, & Chen, 2008). Ideally, with the necessary resources, future research should utilise an allostatic model, whereby a range of allostatic biomarkers (as described in chapter three; 3.6.1.1) are assessed to determine the impact of stress across a number of physiological systems including neuroendocrine, cardiovascular, immune and metabolic (Dowd & Goldman, 2006; Seeman, Mcewen, Singer, Albert, & Rowe, 1997). By doing so, systems involved directly with the stress response, but also those impacted by repeated activation of the stress response can be explored in relation to perceptions of stress, resilience and other psychosocial factors to develop a detailed understanding of the pathways towards both psychological and physiological outcomes in chronically stressed populations.

6.5.5.3 Questionnaire measures

Decisions were made regarding the number of questions participants would be required to complete whilst taking participant burden into consideration. The inclusion of some additional factors may have provided greater context or highlighted variables that required controlling within statistical analysis. Young carers identified as members of a young carer population and were asked who they cared for and what condition(s) they were involved in the care of; however, they were not asked the duration of their caregiving, or how many hours of caregiving they provided per week. Yet this may have been challenging, as some of the young participants found it difficult to conceptualise time scales within the measures included in the study. The social-readjustment scale requires participants to respond based on the past year of their life and some participants needed prompting or a time anchor (i.e. “it’s been a year since our family holiday”) in order to complete the scale. Young carers who begin caring at a young

age or who have always lived within a caring context, may not be able to identify when their caring responsibilities began. With regard to assessing the hours of caring per week, many participants found it difficult to quantify how many hours they spent outdoors and parents or the researcher assisted them in calculating this. Therefore, if questions regarding duration and hours per week of caregiving are to be included, it may be necessary for this to be done alongside parents, guardians or older siblings who can provide context and support to ensure that estimates are as accurate as possible.

A further limitation regarding the questionnaires relates to the matched control sample who were recruited on the basis that they did not identify as providing care in the family home. Despite this, and considering that many young carers do not realise they are young carers (Ronicle & Kendall, 2011), some controls may have had illness or disability within their family and unknowingly be providing some level of care. In order to address this, a simple question asking control participants whether any family members had a health condition, illness or disability and whether they help this family member in anyway would be sufficient to identify where there may be potential caregiving taking place. Finally, it may have been useful to request information surrounding the family structure, particularly as research has found that young people in lone-parent families are more likely to become young carers than those where both parents are present (Dearden, 2004).

6.5.5.4 Study sample

Despite the earlier limitation regarding ethnic representation, overall, young people were recruited from a range of ethnic backgrounds including White British, Black British, Indian, Pakistani and Chinese. Furthermore, of the ten levels of deprivation, eight were represented within the sample and all years of age between 11 and 18 had at least two participants. Given the size of the sample and the limited geographical region in which recruitment took place, the sample overall was relatively diverse. Despite this, greater representation of ethnic minorities could be achieved, alongside recruiting a sample over a broader geographical area to account for differences between regions and include urban, suburban and rural locations.

A power analysis was conducted prior to data collection to determine the sample size required, despite this, recruitment was challenging and with the omission of outliers, the overall number of participants did not reach the required number. This could explain the non-significant group differences and the non-significant regression analyses for hair cortisol concentration. As described in the methodology (chapter three; 3.8.2) a number of steps were taken to recruit young carers and despite strong links and collaborations with a local carers' centre, overall the process was challenging, as is often the case in research with young carers (Kennan, Fives, & Canavan, 2012). All carers' centres, charities and organisations within the South West of England, South East of England and the South of Wales were contacted with information about

this study, however future research may benefit from extending their remit of recruitment, particularly if carers' centres are willing to host a data collection event, as was the case for a number of centres involved in the current research. Not only would extending the geographical reach of recruitment benefit sample size, it would also diversify the sample as discussed above. Future research with a larger sample size, and thus greater statistical power, would enable more reliable analyses of the data and for firmer conclusions to be drawn, particularly surrounding group differences and whether they are due to a type 2 error.

6.5.6 Conclusions

The present study sought to explore group differences in perceived stress and hair cortisol concentration in young carer and non-carer samples, and to identify the relationships between perceived stress, resilience, and hair cortisol concentration and the psychosocial factors that may contribute to the variance of these three variables. The study found significant group differences on perceived stress but not hair cortisol concentration. Positive associations were found between perceived stress and resilience in both groups, and between perceived stress and hair cortisol concentration in the young carer sample only. Caregiver status, resilience and avoidant coping contributed to variance in perceived stress scores, whilst family support, social support, benefit finding and perceived stress contributed to resilience. With regard to the variance in hair cortisol concentration, no significant contributing factors were identified, and the limitations surrounding this have been discussed above.

Although causation cannot be inferred from correlational analysis, findings show a relationship between perceived stress and resilience, providing guidance for future research and potentially future interventions with young carers and general adolescent populations. A longitudinal study is necessary to determine whether the psychosocial factors contributing to variance in perceived stress and resilience in this study are predictors of these outcomes, and a larger sample will enable a greater number of factors to be explored in analyses. Whilst this initial research needs to be appropriately interpreted with the limitations discussed above in mind, organisations may benefit from promoting the factors identified as contributing to perceived stress and resilience in their service offerings and activity programmes.

Overall, the study used a novel application of cortisol assessment via hair samples in a physiologically underexplored population, who for the most part, found this method of sampling acceptable. To date, this is the first study to assess hair cortisol concentration and one of the few to assess a physiological biomarker of stress in a young carer population.

The findings of this study not only provide a basis for future research, which will be discussed in the next chapter, but also extends the current caregiving literature. By identifying factors associated with perceived stress and resilience in young carers this study addresses some of the gaps that currently feature when considering caregiving across the lifespan, that is from youth, through adulthood and into old age.

6.6 Chapter summary

This chapter has presented the background and method of a quantitative study utilising questionnaires and hair cortisol concentration to assess psychophysiological resilience in a population of young carers (aged 11 to 18 years) and a matched control group of non-carers. Findings were mixed when considered alongside previous literature and the implications of this have been discussed. The strengths and limitations of this study have been explored and suggestions for future research have been made.

Chapter seven: Overall discussion

7.1 Chapter overview

This chapter begins by revisiting the context and rationale of this programme of research. It then moves on to discuss the specific rationale, aim and findings of each of the individual studies. Previous literature, potential implications and the theoretical and methodological contributions are discussed. The research questions are then individually addressed, drawing together the findings of the entire research programme. The strengths and limitations of the overall research are presented alongside suggestions for future work. Finally, an overall conclusion of the thesis is provided.

7.2 Context and rationale

Informal carer research has been criticised for typically focussing on negative or adverse outcomes, despite evidence showing that positive outcomes and benefits exist (Branscum, 2010). It is imperative to acknowledge the challenges and negative outcomes associated with caregiving as a young person, however many have called for research taking a resilience approach, enabling focus on positive outcomes to develop explanations for individual differences and trajectories (Dearden, 2004; Newman, 2002). Focussing on pathways towards outcomes allows identification of potential points and forms of intervention. Trajectories towards negative consequences can be redirected by harnessing protective factors that contribute to resilience. By giving young carers an opportunity to reflect on the challenging aspects of their caregiving, whilst also considering the resources they have to enable them to overcome such aspects, a resilience perspective has been taken in the current research. In doing so, factors contributing to positive outcomes and potential resilience have been identified. This programme of research is novel in that it is one of a limited number to take a resilience approach in a young carer population.

In 2011, a biopsychosocial approach to young carer outcomes was virtually non-existent in the literature (Simon & Slatcher, 2011) and to date this has remained the case. The consideration of the biological, psychological and social impact of youth caregiving through interviews and quantitative study, informed by a systematic review, means a biopsychosocial approach has been taken in the current research. A holistic overview of young carer outcomes and potential pathways towards resilience have been identified. The studies in this programme of research recognise that the biological, psychological and social consequences of caring do not occur in isolation, but they interact to produce complex outcomes that require further exploration.

The three studies in this programme of research were of a sequential design, each building on the other to contextualise previous carer literature in a young carer population. It also gave voice to carer experiences to identify factors that may have been unique to young

carers and quantitatively confirmed which of these factors contribute to outcomes in this population, whilst also comparing young carers and non-carers. Without the qualitative interviews, the quantitative study may have lacked context or relevance to young carers and thus the sequential, mixed methods design was appropriate.

7.3 Study one

After a general literature review suggested a lack of literature surrounding informal carer adjustment and resilience, a systematic review was conducted. The aim was to systematically assess the carer literature to identify the extent and nature of existing studies. Resilience is conceptualised as positive adjustment in the face of adversity, where protective factors can negatively the impact of risk factors, such as caregiving. As such, the systematic review also aimed to identify potential protective factors in a general informal carer population to provide a basis for subsequent young carer research.

The review found that problem-focussed coping is associated with positive adjustment, to a greater extent than emotion-focussed coping, thus supporting the forms of coping highlighted within the transactional model of stress and coping (Lazarus & Folkman, 1984). The identification of coping styles that both promote and inhibit positive outcomes in carers also provides support for the distinction between maladaptive and adaptive coping strategies in this population (Lazarus & Folkman, 1984). Cognitive strategies (acceptance and appraisal), and social support were positively related to adjustment, particularly physiologically. Methodological issues were identified within the included studies and highlighted gaps within the literature. A strong call was made for research that addresses the imbalance between studies using only psychosocial measures and the few using physiological measures. Longitudinal research is also needed to provide predictive data and studies with young carers are necessary to determine the impact of caregiving across the lifespan.

The systematic review provides a unique contribution to the informal carer literature as previous reviews typically focussed on a specific type of carer (e.g. Dementia, Stroke, Cancer) or a specific adjustment factor (e.g. coping style or social support). This review focussed on a range of adjustment factors and all types of carers and found support for the transactional model of stress and coping as proposed by Lazarus and Folkman (1984). Previous reviews have tended to describe or collate the needs of carers, or provide data on prevalence and outcomes, rather than factors which may promote outcomes. In contrast, this systematic review identified specific factors which may be protective and promote resilience in carers, enabling these factors to be explored further and potentially harnessed to promote pathways towards positive adjustment. It provided a basis for the subsequent studies in this programme of research but also provides others with a foundation upon which to build future research, particularly as specific methodological issues and recommendations have been identified (chapter four; 4.5.5 and 4.6.2).

7.4 Study two

Given the findings of the systematic review, to further explore the potential protective factors identified, specifically in young carers, a qualitative study was conducted (chapter five). The study aim was to determine whether factors identified in the systematic review were applicable to young carers and whether there were any additional factors of relevance to this population. Evidence was also sought for the relevance and applicability of the socioecological framework of resilience (Windle et al., 2011) in a young carer population.

Work with young people has been criticised for not being child-centric and failing to adopt suitable methods for children and adolescents (Kennan et al., 2012). Therefore, the qualitative phase of this research used photo elicitation interviews as they are well suited to young people and have been used effectively in previous child and adolescent research (Miller, 2016).

After conducting interviews using photos taken by young carers to elicit responses, thematic analysis was conducted. Eleven key themes were identified across the three levels of the socioecological framework of resilience, providing support for not only Windle and Bennett's (2011) framework in the context of caregiving, but also the earlier and more general socioecological resilience theories of researchers such as Garmezy (1991) and Werner and Smith (1982). The four themes of pre-empting challenges and planning ahead, cognitive strategies, emotional strategies and seeking solitude were identified at the individual level. The three themes of family support, friendships, and pets and inanimate objects were identified at the community level, and finally, the four themes of professional support, access to carer activities and community, being outdoors and disability aids were identified at the level of society, which includes environmental factors. It was concluded that the socioecological framework was supported by qualitative data collected from young carers and that factors identified within the systematic review were also confirmed (as will be discussed in greater detail below).

These findings support previous research which has concluded that having a parent with an illness is not always a difficult experience for young people (Bogosian et al., 2010). The findings are in line with previous literature identifying benefits and positive psychosocial outcomes in youth caregiving including social recognition (Pakenham & Cox, 2014a), gratification (Becker, 1995), the developmental of important life skills (Thomas et al., 2003), feeling equipped to live away from home (Rose & Cohen, 2010) and finally, the development of closer family relationships and greater family support (Kuuppelomäki et al., 2004). Rose and Cohen (2010) state that young carers can feel a sense of pride and confidence as a result of their caregiving responsibilities which were benefits identified by the young carer sample during the interviews. It has been suggested that these positive feelings can be a result of the social recognition young carers receive but also a sense that they are constructively contributing by

providing care to the person they care for (Day, 2015). A number of carers highlighted factors surrounding their recognition and the value they gained from their experience, particularly when family members expressed gratitude or acknowledged their contribution. Furthermore, throughout the accounts of young carers it was evident, especially when reflecting on benefits, that their caregiving role had helped them to develop maturity and life skills that would be beneficial in the future, factors which have been identified in previous literature (Ireland & Pakenham, 2010; Lloyd, 2013; Rose & Cohen, 2010; Thomas et al, 2003). These particular benefits suggest that the role of caregiving at a young age may not only have positive effects during the period of caring, but that these benefits may extend to other points and developmental periods across the lifespan. The accounts of young carers reflected previous findings whereby they seek to control their situations using strategies such as thinking and planning ahead to reduce anxiety and uncertainty about the person they are caring for (Earley et al, 2007; Rose & Cohen, 2010). Evidence was also found to support previous literature that identified that carers seek to maintain control by pursuing information relevant to the condition they were caring for (Haley et al, 1987) and try to maintain close proximity to the individual receiving care (Earley et al, 2007). Research surrounding familial relationships in the context of youth caregiving is mixed. Barnett and Parker (1998) identified a lack of familial communication within families with a young carer whilst Kuupelomaki et al (2004) found young carers described feeling closer to the person they care for. In the qualitative study it was noted by participants that rather than having a negative impact upon familial relationships, being a young carer enhanced family cohesion and led to closer family relationships than young carers believed their peers to have, this is in line with previous research which found that the relationship between the young carer and the individual being cared for was strengthened and that during periods of care family members became closer (Ireland & Pakenham, 2010; Lloyd, 2013; Rose & Cohen, 2010; Thomas et al, 2003). The current qualitative study drew the same conclusion as Pakenham and Cox (2010) in that the role of a young carer does not necessarily lead to negative consequences, and with adequate support, such as the community and professional support described in interviews, many young people can cope effectively.

The qualitative findings extend literature that has identified adult and elderly carers use problem and emotion-focussed coping by identifying this is also the case in young carers (Haley et al., 1987; Kim et al., 2003; Sander et al., 1997) and thus provides further support for the transactional model of stress and coping (Lazarus & Folkman, 1984) within a young carer population. Evidence of problem solving coping, seeking social support, acceptance and avoidance were found in the qualitative analysis, supporting quantitative research with young carers (Pakenham & Bursnall, 2006). Social support was a key factor for interviewees and young carer accounts highlighted that support from family, friends and siblings was important, as found in previous literature surrounding social support and young carers (Ali et al,2013).

Although negative outcomes were not specifically explored in the interviews, some young carers provided evidence for outcomes that have previously been identified in the population. Due to the level and intensity of some young carers' responsibilities, many lack opportunities to socialise with peers (Aldridge & Becker, 1993c) and to access out-of-school activities such as clubs or holiday programmes (Dearden & Becker, 1998). Some young carers expressed that accessing activities was difficult without the practical support of other family members, for example to have transportation when needed. Others identified that their caregiving role limited their social activities and it wasn't until external assistance was used that young carers could socialise with peers. Furthermore, evidence was found to support previous findings that young carers have anxiety surrounding the condition of the person they are caring for and find it difficult to disconnect from their caregiving responsibilities (Ali et al, 2012). This was particularly the case when activities were for extended periods of time such as a whole day or a number of days, where young carers needed to remain in contact with their family and utilise professional support in order to allay any anxieties or worries they may have had about their family member.

The qualitative study in this programme of research, alongside existing carer literature provided a basis for making decisions surrounding which variables to measure in the quantitative phase of this research. Rationale for the measurement of family support, friend support, coping and benefit finding was provided by the systematic review and qualitative study. Furthermore, to date, this is the first study to use photo-elicitation with young carers and did so successfully, offering levels of autonomy, freedom, creativity and ownership that a traditional interview may not have (Carter et al., 2015; Jorgenson & Sullivan, 2009; Mandleco, 2013). This research placed the young person in the centre of the research process. Feedback surrounding photo elicitation was informal and not recorded, therefore can only be deemed anecdotal, however many participants and their parents found the experience positive. Some highlighted that the process of taking photos and discussing them was useful in the family context, particularly where little conversation had taken place within the family surrounding the young carers role. Participants and parents expressed that participation allowed them to step back and evaluate the role, acknowledge difficulties faced but also their ability to cope. Photo elicitation promoted a sense of openness and sparked conversation within families, with some parents commenting they had not realised for example that their child enjoyed the role. In some ways, the photo elicitation method acted as an intervention in itself, having a positive impact on young carers and some members of their family. With this in mind, future research may seek to evaluate this method further, so that charities and organisations working with young carers may consider photo-elicitation as an intervention or activity to promote family relationships, conversation and recognition of the young carer role within a family context. Given that creativity was reported as an important part of emotional expression and regulation, activities surrounding photo taking and their caregiving role may offer an autonomous way to engage

young carers in one-to-one support or interventions. Further research evaluating the approach would be necessary to determine if this was plausible and effective.

The qualitative findings contribute to factors identified that services may wish to promote in support and activities. Appraisal (and thus perception) of resources are a key element of the transactional model of coping (Lazarus & Folkman, 1984). Though not statistically identified as contributing to perceived stress or resilience, factors in the qualitative study are the resources young carers perceived themselves to have and to be helpful. Services may incorporate factors highlighted in interviews into their support and activity offerings. For example, an activity where non-carer friends can be included, involving animals whilst being outdoors may enable young carers to benefit from such protective factors and resources. Finally, the findings of this study offer empirical evidence and rationale for continued funding into services that support young carers and further research so that services may develop strong arguments and justifications for the provision of their activities and support.

7.5 Study three

Having identified potential resilience factors in a general caregiving population via the systematic review and more specifically in interviews with young carers, quantitative assessment of protective factors was important to identify potential pathways towards specific outcomes. Doing so enables pathways towards negative outcomes to be diverted by harnessing protective resilience factors and promoting positive outcomes and adjustment.

Previous research investigating physiological outcomes in relation to chronic stress, particularly the chronic stressor of caregiving, has been criticised for being adult centric (Earley & Cushway, 2002). The carer literature is dominated by studies investigating physiological outcomes in adult and elderly carers, but not young carers. Due to the lack of studies using biomarkers of stress to assess physiological outcomes in young carers, it was a priority to measure the stress biomarker of cortisol in this population. By also measuring psychosocial factors, the study took a biopsychosocial approach, whereby a holistic picture of young carer outcomes and trajectories could be developed, an approach to research that has been called for by researchers, particularly in the context of resilience (Dhabhar, 2013). The study aims were to explore group differences in perceived stress and cortisol concentration in a young carer and matched non-carer sample, and to examine factors contributing to the variance of perceived stress, resilience and cortisol concentration.

Young carers reported significantly greater perceived stress than non-carers a finding that supports previous literature whereby Vedhara et al (2002) found that non-elderly carers reported higher levels of self-reported stress than non-carers, and Faulkner and Davey (2002) found that young people living with parental illness are at a higher risk of displaying stress symptoms than those with healthy parents. Whilst the measures in this study and those in the

current research differ, the between group comparison of perceived stress supports the findings of Faulkner and Davey's (2002) study.

Unlike previous studies in adult and elderly carers, no differences were found in cortisol concentration between carers and non-carers (Faw, 20816; Kim & Knight, 2008; Kudielka, Hellhammer, & Kirschbaum, 2007; Moriguchi Jeckel et al., 2009; Stalder et al., 2014). This is however in line with research identifying that young people living with parental illness report greater stress but do not have higher cortisol compared to young people living without parental illness (Turner-Cobb et al, 1998; Sieh et al, 2012) and further supports Vedhara et al's (2002) findings whereby non-elderly carers and non-carer controls did not demonstrate significantly different endocrine or immune outcomes. The findings of the current quantitative study may be indicative of the conclusions of Vedhara et al (2002) whereby compared to elderly carers, those who adopt a caring role at a young age may demonstrate physiological resilience due to their young age and the subsequent relative lack of allostatic load they have.

A significant negative association was found between perceived stress and resilience in both young carers and non-carers. Few carer studies specifically report findings surrounding perceived stress and resilience where the latter is measured using a specific resilience measure and instead use the term resilience as an all-encompassing or proxy term for general psychosocial outcomes. Despite this however, the finding that greater self-reported resilience is associated with lower perceived stress scores is reflective of the general stress and resilience literature which associates resilience with less perceived stress (Wagnild & Collins, 2009). Although not specifically measuring perceived stress, a study investigating resilience in relation to general psychological outcomes in adult and elderly carers found that resilience was negatively correlated with adverse outcomes such as depression, anxiety and emotional problems (Rosa et al, 2018). The findings of the current quantitative phase of research support the general argument that resilience can contribute to positive and negative outcomes in populations of carers.

A significant positive association was found between perceived stress and hair cortisol concentration in young carers only, supportive of research that has found greater perceived stress is positively associated with cortisol in carers. Unlike previous literature, a link between resilience and cortisol was not found in the current study (Ruiz-Robledillo et al, 2014). No significant associations were found between resilience and hair cortisol concentration for either group.

A significant negative association was found between benefit finding and perceived stress in young carers only, supporting previous literature which has identified that benefit finding is negatively associated with perceived stress in female carers of all ages (Cassidy, 2013) and in young carers (Cassidy, Giles & McLaughlin, 2014) . No significant associations were found between benefit finding and hair cortisol concentration for either group, an area of research that has not yet been explored. As non-significant relationships were found between

variables, analysis of benefit finding and resilience as individual mediators of the relationship between perceived stress and hair cortisol concentration were not conducted as planned.

In addition to resilience, caregiver status and avoidant coping significantly contributed to variance in perceived stress, in line with previous literature that has identified emotion and avoidant focussed coping contributes to negative psychosocial outcomes in carers as identified in the systematic review (Chapter four). In addition to perceived stress, family support, social support and benefit finding significantly contributed to variance in resilience. This provides evidence for a positive link between social support and resilience in young carers, as has been the case in adult and elderly carer literature, whereby social support positively influenced resilience and contributed to variance of this factor (Cassidy et al., 2014; Wilks & Croom, 2008). Previous research with carers under 26 years old identified that social support was the strongest predictor of adjustment (Ali et al, 2013). The findings of the current study identified that family support was the strongest predictor of variance in the adjustment measure of resilience, whilst social support and benefit finding were almost equal in the amount of variance in resilience they could account for. The findings of the regression with resilience as the outcome measure, support the argument that benefit finding is associated with and may promote resilience as identified in adult (Cassidy, 2013) and young carers (Cassidy & Giles, 2013; Cassidy et al., 2014). Though a number of studies have not explicitly defined and measured resilience specifically in relation to benefit finding, many have concluded that benefit finding promotes positive adjustment and quality of life in adult and elderly carers (Ireland & Pakenham, 2010; Kim et al., 2007; Pakenham, 2005a; Simpson & Jones, 2013). This is supported by the current research which identified that benefit finding was positively associated with and contributed to the variance of resilience.

No significant contributory factors were identified for variance in hair cortisol concentration, including when the interaction between social support and resilience was entered as a moderator into the regression analysis. Unlike previous studies in adult and elderly carers, no associations were found between social support and cortisol (Faw, 2016; Kim & Knight, 2008).

Overall, the findings of the quantitative study, particularly surrounding psychosocial factors, are supportive of previous literature, whilst findings regarding physiological outcomes are more mixed, much like previous physiological research in carers across the lifespan.

To date, this is the first study to measure cortisol levels in young carers, using hair samples, a method that is gaining popularity but has been used very little in child and adolescent research (Prado-Gascó et al., 2019). This study goes some way to address criticisms that young carer research fails to objectively assess physiological outcomes and take a biopsychosocial approach to explore young carer resilience.

Efforts were made to make the quantitative study protocol as accessible and acceptable to young people as possible. This was achieved through active, informal consultation with

prospective participants during the design of the study due to an on-going collaboration with a local carers' centre. Physiological sampling methods were informally discussed at a young carer group, giving the opportunity for young people to be involved with the development of the research. Hair samples were deemed the most suitable and favoured, and were collected in a way that was appropriate and understandable to young people whilst offering autonomy. This study therefore makes a methodological contribution, demonstrating that hair samples are an acceptable method for biomarker assessment in adolescents but also more specifically, young carers. In particular, this study moved away from using symptom inventories or self-reported health to determine physiological status as has been the case in much of the previous literature surrounding young carer outcomes which is predominantly descriptive or subjective in nature (Pakenham et al, 2006). Unlike self-report measures, the assessment of physiological biomarkers such as cortisol enables an objective measure of physiological status to be made, a strength of the current quantitative study conducted.

Overall, the quantitative phase of this research identified factors contributing to variance in perceived stress and resilience, including social support, family support, avoidant coping and benefit finding. Additional research is needed to further elucidate the pathways leading to outcomes of perceived stress, resilience and hair cortisol concentration, however services and organisations may promote or manage these factors in activities or support for young carers. In doing so, they may harness protective factors, reduce perceived stress and promote resilience in this population.

7.6 Overall findings

The overall findings of this programme of research will now be discussed and integrated in order of the research questions presented in the introduction chapter of this thesis (chapter one; 1.5).

7.6.1 What factors contribute to resilience and psychophysiological adjustment in general informal carer populations?

As the only study to focus on a general carer population, study one (systematic review) addressed the first research question. The evaluation of the caregiving literature identified key resources used by carers of all ages and providing care for a range of conditions. A general overview of factors associated with coping and adjustment was obtained, which could be further explored in young carers. Factors identified included problem-focussed, emotion-focussed and cognitive coping strategies, stress-appraisal, religious coping, social support, family resources, daily hassles, perceived choice, resilience trait anxiety and burden.

7.6.2 Are resilience factors identified in the general informal carer population the same or different in a young carer population?

Study one and study two (qualitative study) address the second research question. The systematic review included one study that focussed on young carers (Pakenham et al., 2006) which found social support, stress appraisal, problem-solving, seeking support and acceptance were positively associated with good adjustment, whilst avoidant coping was associated with poor adjustment. These findings are reflected in the general carer literature confirming that some resilience factors identified in the general carer population are the same in a young carer population.

Study two found that apart from religious coping, all factors identified within the systematic review (general carers) were present in the qualitative accounts of young carers. This indicates again that factors identified in the general carer population are the same in a young carer population. Additional factors were identified including pre-empting challenges, seeking solitude, pets and inanimate objects, professional support, access to carer activities and community, being outdoors and the use of disability aids. Some of these factors have empirical support from the general caregiving literature, however these did not meet criteria for inclusion in the systematic review. These factors have however been discussed in relation to previous literature where available in the qualitative chapter (chapter 5; 5.5.1 to 5.5.3). As some of these factors have not been identified in a general caregiving population, these findings suggest that there are protective factors that may be specific to young carers. Therefore, this research question was addressed via the identification of resilience factors in young carers that were both the same and different to the general carer population.

7.6.3 What factors contribute to perceived stress, resilience and physiological outcomes in young carers?

Study one, two and three (quantitative study) aimed to address the third research question. One study in the systematic review was related to young carers, the findings of which partially address question three by determining that social support and acceptance were positively associated with perceived stress (Pakenham & Bursnall, 2006).

Study two identified factors young carers perceived to contribute to their stress, coping and adjustment, predominantly problem-focussed coping, emotion-focussed coping, cognitive strategies, seeking solitude, social support, and carer activities and community

Study three developed these findings and quantitatively assessed the factors identified thus far in relation to perceived stress, resilience and physiological outcomes. Evidence was found for a negative association between resilience and perceived stress (that is, greater resilience scores were associated with lower perceived stress scores), whilst caregiver status and avoidant coping contributed to greater perceived stress scores. Family support, social support and benefit finding positively contributed to resilience, whilst perceived stress negatively contributed. Although perceived stress and hair cortisol concentration were positively associated

in the young carer sample, no other factors were identified to account for variance in hair cortisol concentration. Thus, on the basis of these findings, the factors of caregiver status, avoidant coping, family support, social support and benefit finding were identified as contributing to perceived stress and resilience.

Overall, a number of factors were qualitatively identified as impacting the outcomes of perceived stress and resilience in young carers, whilst in the quantitative study five factors were identified as contributing to perceived stress and resilience. Due to non-significant relationships between psychosocial factors and hair cortisol concentration, research question three was only partially addressed.

7.6.4 Do young carers and non-carers show similar or different psychophysiological stress profiles?

The systematic review and qualitative phase focussed only on carers. It may have been interesting to conduct interviews with non-carers and compare findings surrounding potential protective factors, however the purpose of the interview study was to build upon the systematic review and provide specific young carer context to develop quantitative protocol. The quantitative study recruited a non-carer sample enabling comparison between young carers and non-carers and thus was the only study to address research question four.

Statistical comparisons of groups found young carers report significantly greater perceived stress than non-carers but do not demonstrate significantly higher hair cortisol concentration. Thus research question four is answered with evidence that young carers and non-carers show similar physiological stress profiles but different psychological stress profiles.

The finding surrounding perceived stress is in line with previous caregiving literature where carers report greater perceived stress compared to non-carers (Pinquart & Sörensen, 2003). Salivary cortisol research has typically found that elderly carers demonstrate greater cortisol levels than non-carers (Davis & Cowen, 2001; Kim & Knight, 2008). However as carer age decreases the findings become more mixed, with adult (non-elderly) carers demonstrating less pronounced neuroendocrine dysregulation (Gallagher et al., 2008; Gallagher, Phillips, Drayson, & Carroll, 2009; Lovell et al., 2012a; Vedhara et al., 2002). Furthermore, children living with parental illness, but not explicitly defined as carers, have shown no difference in cortisol levels compared to non-carer controls (Turner-Cobb et al, 1998; Sieh et al, 2012). Though the interpretation of such findings need to be taken with caution due to the limitations discussed in the previous chapter (chapter 6; 6.5.5), the finding that young carers do not have greater hair cortisol concentration than non-carers is not in line with the elderly carer literature but instead supports previous research with children and adolescents in the context of parental illness (Turner-Cobb et al, 1998; Sieh et al, 2012).

7.6.5 Relating overall findings to theory

The findings of the current research programme can be related to the theory and models outlined in the literature review (chapter 2; 2.3 and 2.4) including allostatic load, the transactional model of stress and coping (Lazarus & Folkman, 1984) and the socioecological framework of resilience for carers (Windle & Bennett, 2011).

7.6.5.1 Allostatic load

Limited evidence was found to support allostatic load theory, whereby neuroendocrine systems are unable to maintain balance due to repeated exposure to stress, most frequently resulting in elevated cortisol levels. The quantitative study revealed a significant, positive association between perceived stress and hair cortisol concentration in young carers. This indicates that greater perceived stress is associated with greater hair cortisol concentration, a sign that perhaps young carers are experiencing allostatic load. Despite this finding, no evidence was found for the contribution of perceived stress in the variance of hair cortisol concentration and the limitations surrounding this have been discussed in the previous chapter (chapter 6; 6.5.5.2).

7.6.5.2 Transactional model of stress and coping

The findings of both the quantitative and qualitative phases of this research are supportive of the transactional model of stress and coping (Lazarus & Folkman, 1984), where the interaction between an individual, their environment and coping strategies are considered important. There is strong emphasis on the distinction between emotion and problem focussed coping strategies for which evidence was found in the qualitative and quantitative phase of this study. Themes from the interviews included reference to problem solving strategies such as pre-empting challenges and thinking ahead which were deemed helpful by young carers, but also emotion focussed strategies such as emotional expression, creativity and distraction which were also of value. The systematic review provided strong evidence for the stress-coping model in the general carer literature demonstrating that many studies identified factors associated with adjustment which are in line with problem and emotion focussed coping, cognitive strategies and general coping style. Finally, in the transactional model of stress and coping, stress is viewed as an ongoing and interactive process, whereby an individual and their environment interact (Sarafino, 1998). Evidence for this view was found throughout this programme of research, with findings demonstrating both individual and environmental factors at play in the population of young carers.

7.6.5.3 Socioecological framework of resilience

Findings from the systematic review, the qualitative interview study and the quantitative study all provide support for the socioecological framework of resilience (Windle

& Bennett, 2011). This framework, classifying protective factors in the context of stress on the level of individual, community and society has qualitative support within the caregiving context when applied to older spousal dementia carers (Donnellan et al., 2015) and can also now be applied to young carers. Windle and Bennett (2011) argue that carers depend on individual assets to manage their situation, but also interact with their environment via social and community resources. Findings of this programme of research support this argument, in that young carers have individual factors enabling them to manage their situation, but also utilise resources in the immediate and wider environment such as family support, friendship and professional services. Evidence is provided for the process based definition of resilience – whereby a dynamic process involving factors on individual, community and societal levels takes place, enabling positive adaptation within the context of significant adversity. In this case, caregiving as a young person is conceptualised as a risk factor given the evidence for negative outcomes in this population. However, the potential protective factors identified within this programme of research indicate that positive adaptation is taking place in young carers, enabling positive outcomes and benefits to be identified.

The single young carer study included in the systematic review found lower stress appraisal, problem-solving, seeking support and acceptance promoted positive adjustment, and avoidant coping was associated with poorer adjustment. These are factors identified on the individual level within the socioecological framework. In addition, social support was found to be positively associated with better adjustment, a factor that fits into the community level of the framework. The qualitative study identified 11 key themes as previously described above, within which a number of factors were identified that young carers felt helped them cope and be resilient. Finally, the quantitative study confirmed that family support, social support and benefit finding positively contributed to resilience, whilst perceived stress negatively contributed. All of these findings can be categorised within the socioecological framework of resilience, as has been the case in previous carer literature, and are presented in table 7.1 below. A number of the factors identified are supportive of those presented by Rutter (1979) including planning, family and professional social support, relationships, a positive family atmosphere, tangible support, health services and social support from friends.

Table 7.1

Resilience factors identified within this programme of research, presented by levels within the socioecological framework of resilience and with indication of which study the factors were identified within (✓)

Resilience factors (by level)	Systematic Review	Qualitative Study	Quantitative Study
Individual			
Stress appraisal	✓		
Problem-solving coping	✓	✓	
Seeking support	✓	✓	
Acceptance	✓	✓	
Benefit finding		✓	✓
Emotional strategies	✓	✓	
Seeking solitude		✓	
Avoidant coping	✓	✓	✓
Community			
Social support/Friendships	✓	✓	✓
Family support	✓	✓	✓
Pets and inanimate objects		✓	
Society			
Professional support		✓	
Carer activities & community	✓	✓	
Being outdoors		✓	
Disability aids		✓	

An important consideration is that the qualitative phase of this research revealed that often protective resilience factors do not function in isolation, but instead can promote and facilitate each other in a symbiotic manner. This therefore supports the connections that the socio-economic framework of carer resilience makes between the categories of society, community and individual factors. It is also noted that in some instances, factors do not necessarily fit neatly within the three categories of protective factors and therefore it may be appropriate to place it in more than one, something that at present is not discussed in relation to the framework within the literature. In addition to factors being broader or relevant to more than one category of protective factor, there is support for Luthar et al's (2000) assertion that factors cannot necessarily be easily categorised as protective or risk factors. Indeed, a number of young carers considered their role to be prospectively protective in the sense that it offered skills,

capabilities and strategies that would benefit them in the future, even if not necessarily in the moment. This therefore begs the question as to whether factors can be considered protective or risky depending on the life stage in which they are experienced. Young carers are considered a vulnerable population due to their age and responsibilities (Gray, Robinson, & Seddon, 2008; Gray & Robinson, 2009; Kavanaugh, 2014; Werner & Smith, 1982) however the immunosenescence stance would argue that those in late adulthood and old-age are at more risk from caregiving than those who are younger due to age related declines. In some carers, caregiving may be a risk factor, whilst in others it may act as a protective factor, particularly those who are young carers. This demonstrates the nuances and complexity of not only resilience as a concept, but also the conceptualisation of protective and risk factors, particularly in the context of a biopsychosocial and lifespan approach.

Finally, within the societal level of the model presented by Windle and Bennett (2011) macrosocial factors were theorised to have an impact on resilience. Although young carers did highlight the value of professional and health and social care services within interviews (supporting Werner and Smith's (1982) assertion that protective factors can be both direct and indirect), they did not discuss the impact of the wider factors suggested by Windle and Bennett such as social policy, employment and economy. This is perhaps reflective of the age of the participants who were typically not yet in employment or of voting age, and thus may not have been as aware of the impacts of social policy or economic factors upon their lives and outcomes.

The socioecological model as applied to carers was presented in the literature review chapter (chapter 2; 2.4.4). After the general literature review, the systematic review, the qualitative research and finally the quantitative study, this model can now be adapted and applied to a population of young carers. This is presented below in figure 7.1, whereby evidence from across the programme of research is applied, demonstrating that whilst the model was initially developed with (adult and elderly) dementia carers in mind, the model is also appropriate for the conceptualisation of risk and resilience in a population of young carers.

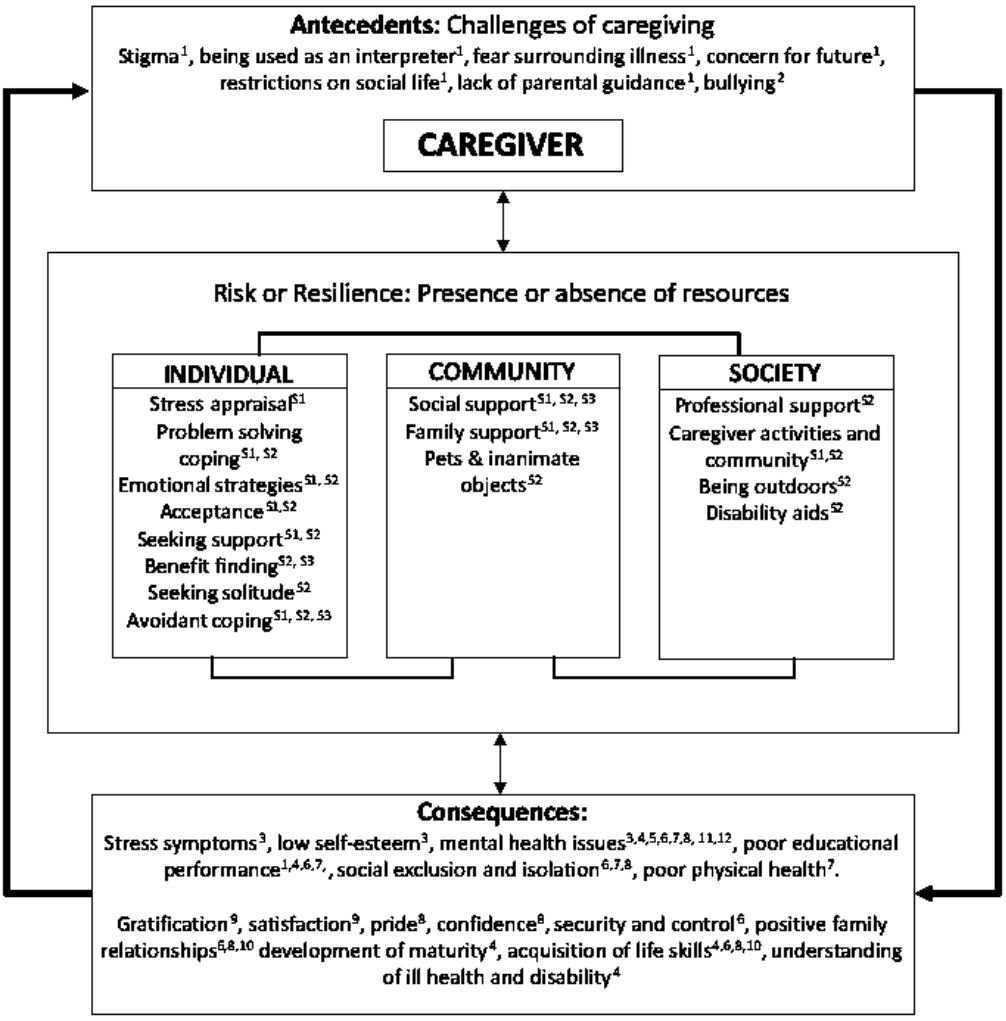

Figure 7.1 Windle and Bennett's (2011) model of resilience modified to apply to young carers on the basis of findings from the current programme of research

Note. [1]Barnett & Parker (1998), [2]Earley, Cushway & Cassidy (2007), [3]Faulkner & Davey (2002), [4]Ireland & Pakenham (2010), [5]Sieh et al (2012), [6]Thomas et al (2003), [7]Aldridge & Becker (1993), [8]Rose & Cohen (2010), [9]Becker (1995), [10]Lloyd (2013), [11]Ali et al (2012), [12]Hamilton & Adamson (2013), [S1]Systematic Review, [S2]Qualitative interview study, [S3]Quantitative hair cortisol study.

7.7 Overall strengths and limitations

The strengths and limitations of the individual studies have been discussed in the relevant chapters, however the overall strengths and limitations of this programme of research as a whole will now be discussed.

7.7.1 The conceptualisation and measurement of stress, coping and resilience

All of the measures in the quantitative study were chosen on the basis of previous validation and their alignment with the definitions chosen to guide this research as outlined in the introduction (chapter one; 1.4). There are some limitations with defining, conceptualising and measuring the factors of stress, coping and resilience.

7.7.1.1 Stress

Stress is considered a multi-dimensional and dynamic concept, whereby the term 'stress' can be used to describe a state of being, a source of challenge and an outcome of the interaction between an individual and a challenging situation (Slavich, 2019). This thesis outlined the definition of stress utilised throughout this research, as the outcome of an interaction with a challenging situation, requiring the appraisal of resources and action to be taken (Lazarus, 1990; Lazarus & Folkman, 1984).

The PSS-10 is a widely used measure in adults, and whilst strongly validated in this group, variations of this scale have not yet been established in general child or adolescent populations (Turner-Cobb & Hawken, 2019). A review of studies using the PSS determined that though not designed for children and adolescents, the scale has been used in many populations including children. The PSS has been adapted for use with young carers (Cassidy & Giles, 2013) and is more suited to this population than the PSS-10. However, the content of the young carer version would not have been relevant to those without caring responsibilities and would not have allowed direct comparisons of perceived stress to be made between carers and non-carers. Further justification for the use of the PSS-10 was provided in the methodology chapter (chapter three; 3.6.2.1.5) however there are issues with applying this scale to young carers.

The PSS-10 assesses perceived stress rather than stress related to specific sources, unlike the Children's Hassles Scale (CHS; Kanner, Feldman, Weinberger, & Ford, 1987) which was not used for two reasons. First, there was clear prominence of the PSS in caregiving literature (Hawken, Turner-Cobb & Barnett, 2018). Second, the CHS features 40 items compared to the ten of the PSS-10 which was deemed more appropriate when considering respondent demands and fatigue. The PSS-10 also captures perceived stress within the month prior to completing the questionnaire and requires participants to retrospectively report their perceptions. This requirement may impact the reliability of findings, particularly as some young people in the current research had difficulty conceptualising the period of one month. Furthermore, the PSS-10 does not specify between acute and chronic stress. Factors associated with stress in the month prior to completing the scale could have been experienced due to an acute stressor, or on going chronic stressor – a distinction that is important when researching chronically stressed groups such as young carers. Given these considerations, the PSS-10 is a reliable but limited measure of stress and can be criticised as other studies have, on the basis that it is unable to capture the many dimensions of stress such as its source, nature, time frame and frequency (Slavich, 2019).

There is a wider debate surrounding the effective measurement of stress and the ability for measures such as the PSS-10 to capture the complexities and nuances of the concept. Although the PSS-10 demonstrated reliability in the current study and sample, there is a need for a scale assessing the complexities of stress in a general youth population which retains

validity when applied to specific groups such as young carers. This will enable between group comparisons.

7.7.1.2 Coping

Opinion varies regarding the definition of coping as either a style, trait or process (Lazarus, 1993) and therefore coping is considered multi-dimensional and both complicated and challenging to measure (Turner-Cobb & Hawken, 2019).

The KIDCOPE (Spirito et al., 1988) was chosen because it measures coping in the target age range of the quantitative study and was developed with the multi-dimensions of coping in mind. The scale assesses numerous coping strategies but does not capture appraisal or the dynamic and situational nature of coping as highlighted in the transactional model of stress and coping (Lazarus & Folkman, 1984). As an exploratory study, using a well validated measure in line with the definition of coping adopted by this programme of research was a priority. Therefore the KIDCOPE was deemed the most appropriate and reliable measure to assess coping in adolescents.

There is however an issue surrounding specificity, whereby quantitative measures are designed for general populations but applied to specific situations such as caregiving. Measures therefore lack specificity and neglect the possibility that coping strategies may vary depending on the stressor involved (Kneebone & Martin, 2003). A review of stress-coping measures found that the decision between population specific, stress-specific or a general measure is a widespread issue in stress and coping research (Steed, 1998). Though using population or stressor specific measures enables specificity, it does not enable comparisons with control groups outside of the specific population or those experiencing the specific stressor. In the current work, the comparison between young carers and non-carers was required to address the research questions and test hypotheses, therefore the most appropriate and validated measures for a general population were chosen to assess stress, coping and resilience in line with definitions specified from the onset of this programme of research.

7.7.1.3 Resilience

Finally, resilience is a difficult concept to operationalise, having been defined in numerous ways as covered in the introduction (chapter one; 1.4.2). The current programme of research defined and operationalised resilience as an active process requiring an interaction between an individual, a challenging situation and their internal and external resources (Rutter, 1979).

Previous resilience research has been criticised for using different resilience definitions and focussing on outcome and effective functioning (Blum, 1998). Some studies have failed to define resilience at all (Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). On the basis of these criticisms and the use of the definition outlined above, a process approach was taken to

capture resilience in the current research. It was therefore necessary to use a measure in the quantitative study that captured this process and assessed a range of psychosocial resources, skills and capabilities at individual, family, peer and environmental levels (Olsson et al., 2003).

The CYRM-28 was chosen as it measures resilience within the domains of individual, community and society, reflecting the levels of resilience factors in the socioeconomic framework (Windle & Bennett, 2011). It is therefore considered a strength that this study adopted a definition of resilience as an interactive process and used a measure of resilience that reflects and is line with the clear definition adopted, addressing previous criticisms of resilience research.

7.7.2 Generalisability and transferability of findings

There are a number of factors that impact the generalisability and transferability of findings, particularly in relation to the recruitment, diversity and demographics of the sample used in the empirical studies.

7.7.2.1 Diversity and representation

The extent of diversity and representation across the studies varied. The qualitative phase of the research was particularly limited as participants were all White British, however the quantitative study was more diverse with regard to ethnicity (White British, Welsh, Black British, Indian, Pakistani and Chinese). Recruitment was limited to the South West of England and South Wales, and recruitment of young carers was a challenging element of this research programme, which is not unusual (Kennan et al., 2012). Census data indicate that the geographical distribution of young carers varies, with the South East and South West of England experiencing the greatest percentage increase in young carers between 2001 and 2011 (ONS, 2013). A national recruitment strategy would diversify the sample and enable wider access to young carers overall, ultimately increasing the generalisability and transferability of findings.

7.7.2.2 Gender

The 2011 census (ONS, 2013) found that similar numbers of males (46%) and females (54%) were young carers. These statistics are not reflected in the samples of the empirical studies. The qualitative study recruited a sample that was 75% female and 25 % male, therefore females were over represented. This was also true in the quantitative study, however the sample was more balanced and closer to national statistics, with 62% female, 36% male and 2% non-binary. Previous young carer research has had mixed proportions of male and female participants. Whilst Lloyd (2013) and Pakenham and Cox (2012) had almost equal numbers of male and female participants, reflective of the national statistics, Thomas et al (2003), Ali et al (2013), Ireland and Pakenham (2010) and Nagl-Cupal et al (2014) had more females than

males. Interestingly, Early, Cushway and Cassidy (2007) and Hamilton and Adamson (2013) had greater males than females. Thus, though it is more common in the literature for samples to be predominantly female, fewer male participants took part in either of the empirical studies. This may be because it can be difficult to recruit male carers due to stigma towards the role and a lack of self-identification, as males typically consider caring to be a predominantly female role (Mills, 2003). This may be overcome by targeting male sports teams and groups such as Scout's or Boy's Brigade and asking if any members have a parent with an illness or disability, and whether they help out in any way at home. It would be important to be respectful and considerate of the possible stigma young males may face for doing so. A more balanced sample in terms of gender would be more representative of the caregiving population in England according to the census data which is important when considering findings of studies may impact interventions which seek to serve young carers within the community.

7.7.2.3 Health conditions

Some caregiving studies focus solely on one type of health condition, or distinguish between mental and physical health conditions. The current programme of research had no exclusion criteria on the basis of health condition and therefore recruited young carers providing care for a wide range of conditions across the two empirical studies (see Appendix H for full list and frequencies by study). This was a benefit in the qualitative study which collected in depth, rich data to explore experiences rather than make direct comparisons between conditions. However, it has been identified that outcomes vary between those providing care for mental health and physical health conditions, with the former experiencing more severe, negative mental health consequences (Hounsell, 2013), specifically anxiety, depression, insomnia and sadness (Thomas et al, 2003). The aim of the quantitative study was to investigate a general young carer population alongside a non-carer age and gender matched control group, rather than compare young carers caring for different conditions. Whilst this may be interesting for future research, an initial exploratory study was necessary and therefore comparisons were not made. Furthermore, it would be difficult to distinguish clear groups where those receiving care have co-morbidities which include both physical and mental health conditions.

7.7.2.4 Recruitment source

All participants in the qualitative study, and 41 of the 50 young carers in the quantitative study, were recruited via carers' centres, charities or organisations which provide support to young carers. Whilst many studies recruit directly from young carers services (Banks et al., 2002; Cree, 2003; Earley et al., 2007; Hamilton & Adamson, 2013; Moore & McArthur, 2007; Pakenham et al., 2007; Smyth, Cass, & Hill, 2011; Thomas et al., 2003) many do not acknowledge the impact this may have on the representativeness of their findings. Recruiting solely from young carer organisations means young people providing care who do not identify

as a carer or do not access services, are not fully represented. Recruiting young carers to participate in research is challenging (Kennan et al., 2012), even more so when young people are not identified as young carers or known to services. This means that those who are most isolated and without support may not be represented in this study, and indeed, the provision of services given to those who took part in the studies may have had an effect on measures such as resilience and social support, as activities may provide opportunities to socialise with friends and develop resilience factors. The challenge of recruiting those young carers who are not receiving support is difficult to overcome, as services provide a point at which to access young carers which does not exist in those not in contact with services. The identification of young carers, as previously discussed in the introduction and literature review chapters is a wider issue which needs addressing through education, awareness and community work, enabling more young carers to be identified and thus provide the opportunity for them to be involved with research and represented within a young carer sample. Perhaps, until greater numbers of young carers are recognised and the underlying issues causing a lack of identification are addressed, such as the stigma and bullying associated with caregiving as a young person (Earley et al., 2007; Lloyd, 2013; Rose & Cohen, 2010), recruiting such a sample will be challenging. Furthermore, until young carers are able to identify as such, efforts to recruit young people who are not having access to carer services will also be challenging, meaning that young carer research will remain biased in its representation of the young carer population, potentially excluding those who are the most isolated or in need of support. Efforts have been made with projects such as the 'Young Carers in Schools Award' and 'Young Carers Awareness Day', but without further funding, higher public awareness and education the issues surrounding the identification of young carers, and their recruitment into studies that seek to support the population, will be inherently difficult. Thus young carer literature will remain limited and the population and those who work with them will remain underserved.

It is imperative to recognise that the young carers involved with the current programme of research may be among the more resilient, due to their access to services.

7.7.2.5 Sample size

A number of steps were taken to increase recruitment success and overall sample size as described in the Methodology chapter (chapter 3; 3.8.2), however the sample size for the quantitative study was still underpowered. Many of the limitations discussed could be overcome through the recruitment of a larger, more representative sample.

In the quantitative study, non-carers were recruited after each young carer had completed data collection in order for matching on age and gender to take place. Recruitment of the difficult to reach population of young carers was considerably more challenging than recruitment of non-carers. Stamatopoulos (2015, pg811) argues that identifying young carers within society is a "difficult and sometimes impossible task" and considers them to be a "hidden

army" due to the lack of their identification. Given the time consuming nature of caregiving (The Children's Society, 2013) and the restrictions already placed upon many young carers' time, it is possible that the empirical studies conducted were too lengthy and time consuming. Though efforts were made to make protocols as short and efficient as possible, they still required a level of commitment. The interview study involved meeting the researcher and being given the camera, taking photos in their own time, waiting for photos to be developed and then completing the recorded interview. Despite this however, the number of participants in the interview study is in line with samples of previous qualitative research utilising focus groups and interviews (Ali et al., 2013; Cree, 2003; Robson, 2004) though some have interviewed up to 20 (Thomas et al., 2003) and over 40 (O'Dell, Crafter, de Abreu, & Cline, 2010) in their studies.

The quantitative study involved less time commitment from the participants and less contact with the researcher, with completion of the questionnaires and hair sampling taking approximately 30 minutes and 10 minutes respectively. When deciding to take part in research, individuals typically consider personal costs (i.e. time) and the possible benefits (i.e. improving wider society or members of their ingroup; Guyll, Spoth & Redmond, 2003). To increase the perceived benefits of participation, particularly for non-carers in the quantitative study, a shopping voucher was provided to thank participants for their time, as this has been shown to increase recruitment success in difficult to reach populations (Guyll et al., 2003). Though sample targets were different for the qualitative and quantitative study, the incentive used in the latter may have contributed to the number of young carers recruited for participation. The sample size of the quantitative study is in line with and in some instances more than those in psychophysiological research conducted with young people living with parental illness (Turner-Cobb, Steptoe, Perry, Axford, et al., 1998; Sieh et al., 2012).

Schools were approached in the local area when recruiting young carers for both empirical studies, a source of recruitment that has been successful in previous literature (O'Dell et al., 2010; Pakenham et al., 2007; Thomas et al., 2003). Many schools did not respond to invitations to find out more information and two communicated that they did not have any young carers within their school. Given the statistics presented in the introduction (chapter one; 1.2) it is unlikely that no young carers existed within an individual school, but rather that young carers had not been identified. Despite programs such as 'Young Carers in Schools' led by the Carers Trust and The Children's Society, schools were not successful sources of recruitment for this study. In 2000, Bibby and Becker stated that schools have been slow to recognise that some children have caring responsibilities. It is not clear why this may be the case, however this was reflected in the recruitment efforts of the current programme of research. This highlights the systematic issues touched upon in the previous chapter with regard to identifying young carers within the general population. It may be that until young carers are more widely recognised and identified, or are willing to be identified, recruitment for studies with this population will be challenging and resource heavy in terms of time scales, researcher input, travel and funding.

7.7.3. Data collection

Having covered the conceptualisation and measurement of key concepts, sample characteristics, recruitment and overall sample size, the strengths and limitations of the overall data collection will now be discussed.

7.7.3.1 Naturalistic environments

Both qualitative and quantitative data were collected in a naturalistic setting for most participants, either their home or at a carers service that they were familiar with. Collecting data in this manner causes minimal disturbance to standard routines in participants (Smit, de Vries, & Poppelaars, 1992). This was deemed important for youth populations with restrictions on their time due to school or extra-curricular activities, particularly for young carers who also face additional restrictions. One disadvantage of this naturalistic environment is that in some cases, when young carers were completing interviews or questionnaires, parents or siblings were present. Although parents did not contribute to interviews or assist directly with answering specific questionnaire items, their presence may have impacted the self-report measures or the interview accounts. It is reported that in the presence of parents, siblings or other family members, young people may find it difficult to be honest, especially when asked personal questions (Harden, Scott, Backett-Milburn, & Jackson, 2000). This is particularly relevant to the current studies as interviews were about the experience of caregiving within the family, and one of the quantitative measures assessed family support. Young carers may find it difficult to report the negative aspects of caring due to a sense of guilt, commitment and loyalty towards the person they are providing care to and have a wish for them to not be blamed about their circumstances (Waugh et al., 2015). Despite this, carers offered frank and honest insights during their interviews, even when parents were present. Furthermore, a wide range of total scores for the family support scale were calculated suggesting that participants were able to honestly report the family support they received.

7.7.3.2 Acceptable data collection methods

The data collection methods used in this research were acceptable to participants and engaging. Photo elicitation received positive anecdotal feedback when used with a young carer population. The quantitative questionnaires were acceptable to all participants who took part in the study, indicating that decisions surrounding the appropriateness and selection of measures were suitable for the age range. Finally, the hair sampling method was accepted by most of the sample, with a small number declining the provision of a hair sample as previously discussed. Importantly, young people, particularly young carers, were informally consulted during the design stages of the research. The researchers collaboration with a carers' centre allowed for young carers to express their views on areas of the research studies such as specific designs and

also the length of protocols. These opinions were respected and implemented within the design, for example the decision to use hair cortisol concentration was supported by young carer preference compared to saliva, blood or urine samples. As a result of this consultation, it is believed that these efforts to involve young carers and young people in the design of the research enabled engaging methods to be used appropriately and with success.

7.7.3.3 Cross sectional design

The systematic review identified that the majority of carer research was cross-sectional in nature, meaning that predictions and conclusions surrounding causation and the long term impacts of caregiving were not possible. As the physical impacts of caregiving can develop over time, a cross-sectional design is often not sufficient to identify these impacts and therefore longitudinal research is recommended (Kim & Knight, 2008). The nature of chronic stress is long-term and enduring, in particular, the chronic stressor of caregiving is characterised by fluctuations in levels of responsibility and perceived stress. A period of remission may entail less responsibility as conditions and symptoms are managed, or more responsibility if the individual receiving care is within the family home. In contrast, a relapse may entail less responsibility if the individual is cared for within a hospital, but may cause greater distress and disruption if hospital visits are required or prognoses are uncertain. This indicates the unique and fluctuating nature of long-term caregiving and thus the requirement for longitudinal research which may be able to capture these variabilities, the nuances and the situational factors that exist within a period of caregiving.

7.8 Future research directions

There is a great deal that future research can do in order to overcome the limitations as discussed above. There are also a number of research avenues that can be taken to further explore the nature of stress, coping and resilience in young carers, three of which will now be discussed.

7.8.1 A family approach

Charities and organisations working with young carers emphasise the importance of taking a whole family approach to provide personalised and effective services (Ronicle & Kendall 2011), potentially because it has been highlighted that within a family there is potential for each member to be impacted in some way by the presence of a health condition (Day, 2015). Given the emphasis on family support in the qualitative accounts of young carers in the current research, and also the finding that family support contributes to variance in resilience, future research may seek to explore the familial impact of youth caregiving by involving family members in protocols. Doing so would allow a more nuanced evaluation of the consequences of caring as a young person, and pathways to resilience, particularly as it has been noted that the

impact of youth caregiving is not limited to the young carer but also impacts other family members (Stein, Riedel, & Rotherham-Borus, 1999). Furthermore, it may bring together the two arguments surrounding the debate of whether young carers should be supported in their role, or whether the individual experiencing ill health should be supported so that children need not take on the role of caregiving.

Quantitatively, investigating psychosocial and physiological outcomes within a family context may provide a fuller picture of the family's circumstances, stress levels and overall resilience. This would enable the young carer to be embedded and studied within this context compared to other family members such as siblings who are not involved in providing care. Research has suggested that family members may have correlated cortisol levels due to shared genetic and environmental factors (Bartels, De Geus, Kirschbaum, Sluyter, & Boomsma, 2003; Linkowski et al., 2017; Steptoe, van Jaarsveld, Semmler, Plomin, & Wardle, 2009). Furthermore, a longitudinal study found that families show similar patterns of afternoon basal cortisol levels, attributable to shared environmental factors (Schreiber et al, 2006). These findings highlight that people are embedded within social contexts which may impact their cortisol levels and therefore it would be beneficial to study these contexts and environments rather than a young carer in isolation.

Qualitatively, given the openness of young carers in the interviews conducted for this research, parent-child dyad interviews could be conducted to provide a fuller picture of the young person's caregiving experience within the family context. Parent-child dyad interviews have been used with success in previous child and adolescent stress research (Cheetham-Blake, Turner-Cobb, Family, & Turner, 2019). When using such an approach, it would be vital to ensure that the young person's story is heard and represented, and that it is not assumed that parents can offer a more truthful or reliable account, as it has been expressed that secondary accounts must not be relied upon when researching child and adolescent issues (Luthar et al., 2000). Given the success of previous parent-child dyad interviews and the family context of caregiving, conducting both quantitative and qualitative research may be of value. Particularly given the responsibilities of young carers within the context of family illness, and with a view to providing family centred intervention or support, as advocated by charities and organisations (Ronicle & Kendall, 2011).

7.8.2 Integrating naturalistic and laboratory based studies

Chronic and acute stressors are rarely experienced in isolation, but are often studied as so, without consideration that both can influence each other (Compas, Orosan, & Grant, 1993). Alongside the chronic stressor of caregiving, young carers may also face acute stressors such as accidents, exams, friendship difficulties or their own ill health. Future research that explores acute stressors within the context of chronic stress may help to determine whether the chronic stressor of caregiving can equip young people to effectively cope with and adapt to acute stress,

thus demonstrating resilience. Alternatively, such experiences may deplete resources and make coping more difficult. Research exploring this would allow a fuller picture of stress responses in this population to be developed.

Questionnaire measures and hair samples could be collected in a naturalistic setting, assessing and reflecting the context of chronic stress. The impact of naturalistic acute stressors, or those experienced in an experimental paradigm such as the Bath Experimental Stress Test for Children (BEST-C; Cheetham & Turner-Cobb, 2016) could be assessed via saliva samples. Finally, diaries could provide qualitative context surrounding stressors and physiological responses to both chronic and acute stressors. An integrated study such as this would more accurately reflect the reality of young carers' lives where both chronic and acute stressors can be experienced in unison.

7.8.3. Longitudinal designs

Although cross sectional designs can be used to predict variance within variables, they do not enable predictions regarding specific outcomes or trajectories over time. Longitudinal studies are required to further illustrate the outcomes of youth caregiving and the potential pathways towards such outcomes. An integrated approach such as that described above could be taken over a longitudinal period to enable reliable and predictive associations to be made between stress events, perceived stress, resilience and physiological outcomes over time.

Finally, to draw firm conclusions about the impact of caregiving as a young person on psychophysiological adjustment across the life span, a study that follows young carers into adulthood is necessary. Although considerable resources would be required, such a study would enable the impact of youth caregiving on psychoneuroendocrine dysregulation in later life to be explored. Furthermore, it may help determine whether the experiences of young carers enable them to develop psychophysiological resilience that benefits responses to other stressors later in life or puts them at a disadvantage.

7.9 Conclusion

Research investigating illness and disability within the family context typically emphasises the adverse and negative impacts of caregiving, but it has been clearly ascertained that though these outcomes exist, positive consequences are also present in caregiving populations (Aldridge & Becker, 1999). Adopting a resiliency approach when researching caregiving allows factors which support adaptation and resilience to be identified and thus applied to appropriately support individuals, and improve their capacity to cope effectively (Svanberg et al, 2010). With this in mind, this programme of research set out to investigate resilience in young carers, to establish factors that may contribute towards individual differences in outcomes and the development of resilience. A number of factors were identified

which may contribute to and promote resilience in a young carer population, providing a basis for future biopsychosocial research with this group.

By taking a child-centric approach, selecting methods on the basis of their suitability for young people and young carers specifically, the findings of the three studies have begun to address the scarcity of literature surrounding young carers, particularly that which takes a biopsychosocial and resiliency perspective. The psychophysiological basis of resilience is under investigated (Dhabar, 2013). Researchers have called for a stronger focus on the biological aspects of risk and resilience (Rutter, 2006) and a developmental approach, so that the influences of stress on immune and endocrine systems throughout the lifespan can be better understood (Graham et al., 2006). The current programme of research directly addresses the criticism surrounding the psychophysiological basis of resilience and contributes towards a limited body of research surrounding the biopsychosocial impact of caregiving, which is even more limited in the context of youth caregiving.

The empirical studies conducted in the current research provide an initial biopsychosocial exploration into a previously unexplored population of young carers. It also provides this population with representation within a wide body of biopsychosocial literature which thus far has typically involved elderly carers (Vedhara et al, 2002) a population that does not represent carers as a whole or across the lifespan.

The findings of the current programme of research extend the theory surrounding resilience in carers, and offers substantial evidence for the suitability and applicability of the socioecological framework of resilience in young carers. To date this framework has only been explored in adult and elderly carer populations. As such, the findings of this research can be used to not only develop future young carer research, but to also provide a basis for the development and implementation of interventions, particularly those aiming to reduce stress and promote resilience in young carers. Furthermore, the findings of the empirical research contribute to the field of PNE and the immunosenescence perspective, offering evidence that may suggest that young carers are not as susceptible to the adverse physiological consequences observed in adult and elderly carers, such as elevated cortisol. This warrants further investigation to fully establish the physiological impact of caregiving as a young person. The physiological assessment utilised in the quantitative phase of this research, makes a methodological contribution to the field of PNE, indicating that hair samples are suitable, accepted and preferred measures in young people, including young carers specifically.

Overall, this programme of research made numerous significant methodological and theoretical contributions, and successfully addressed criticisms of caregiving research to date, adding to the literature surrounding caregiving in general, but particularly the limited literature surrounding youth caregiving, from a lifespan and biopsychosocial perspective.

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Appendices

Appendix A: Systematic Review article published in Health Psychology Open (Study one)

The following article is the author's final copy before journal formatting was applied prior to open access publication. The article is published in Health Psychology Open and can be accessed at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6236498/

Coping and adjustment in caregivers: A systematic review

Abstract

This systematic review assessed coping and adjustment in caregivers of all ages to provide a synthesis of existing literature in the context of methodological approaches and underlying theory. Four databases were searched. Reference lists, citations and experts were consulted. Twenty-seven studies (13 quantitative; 14 qualitative) were included. Coping factors associated with adjustment (problem versus emotion-focussed coping; cognitive strategies) and psychosocial factors associated with physiological adjustment (trait anxiety; coping style; social support) were identified. Results raised methodological issues. Future research requires physiological adjustment measures and longitudinal assessment of the long-term impact of childhood caregiving. Findings inform future caregiver research and interventions.

Keywords

Coping, caregiving, adjustment, caregiver, carer

Background

The impact of informal caregiving has increasingly become the focus of academic research and social policy interest, as health services offer management of what were once serious health conditions, individuals are able to remain in their home whilst receiving care, increasing the need for family members to provide assistance (Schubart, 2014). Carers can be any age (from young child to older adult) and may have various tasks and responsibilities including domestic care, general care, personal/intimate care and emotional support (Kenneth I. Pakenham et al., 2006). Recent census findings (Office of National Statistics, 2012) reported approximately 6.5 million carers in the UK, providing between one and 50+ hours of weekly care, with an average of 24.4 hours per week (Revenson et al., 2014).

Studies have investigated the psychosocial outcomes of caregiving. Compared to non-caregivers, older adult carers report increased stress and depression, as well as lower levels of subjective well-being and self-efficacy (Pinquart and Sörensen, 2003, Revenson et al, 2014). Providing informal care can impact social activities and martital dynamics in adult caregivers (Matthews, 2018). Caring for individuals with specific health conditions (such as dementia) can cause unique challenges, for example being subjected to physical or verbal agression (Dodge & Kiecolt-Glaser, 2016). Furthermore, physical outcomes associated with caregiver stress in both elderly and non-elderly carers, include changes in endocrine and immune functioning (K Vedhara et al., 1999; Kavita Vedhara et al., 2002). Specifically, chronically raised salivary cortisol has been linked to poorer immunity (Pruessner et al., 1999) and young parents caring for a child with developmental disabilities have demonstrated a poorer antibody response to influenza vaccination (Gallagher et al., 2009). Lovell and collagues (2012) investigated psychosocial, endocrine and immune outcomes in young adults caring for a child with Autism Spectrum Disorder or Attention-Deficit Hyperactivity Disorder. Parents reported higher psychological distress, perceived stress, anxiety and depression than non-caregivers and more physical health problems. Although diurnal cortisol secretion did not differ between the two groups, caregivers demonstrated elevated C-reactive protein (CRP), indicating greater inflammatory disease risk. In addition to endocrine and immune findings, health problems including back injuries, arthritis, high blood pressure, gastric ulcers and headaches are also associated with caregiver stress in carers aged 35 to 76 years old (Sawatzky & Fowler-Kerry,

2003). To date research has considered physical outcomes of adult rather than young carers, defined as anyone under 18 years providing care (Becker et al., 2000).

Whilst findings indicate the psychological and physical detriments of caregiving, many caregivers cope effectively without evidence of negative impacts (C. A. Cohen, Colantonio, & Vernich, 2002; Garity, 1997). Positive consequences have been identified; spousal caregivers of cancer patients have reported enhanced relationships, feeling rewarded, experiencing a sense of personal growth and satisfaction (Li & Loke, 2013). Furthermore, informal caregivers of patients with amyotrophic lateral sclerosis report both positive and negative experiences (Sandstedt et al, 2018). Young carers report feeling proud of their role, the development of valuable skills and increased maturity and independence (Cass, Smyth, Hill, Blaxland, & Hamilton, 2009). This suggests not all caregiver outcomes are detrimental, and that resilience may enable effective coping whereby individuals demonstrate adjustment. In the current review, coping is considered a process leading to adjustment, where adjustment encompasses the psychophysiological outcomes of coping; positive adjustment is defined as adaptive response to a challenge, across physical, interpersonal, cognitive, emotional and behavioural domains (Larsen & Lubkin, 2009). The term adjustment was used in this review as it encapsulated a number of terms that relate to outcomes in the caregiving context and is most often used in this particular field.

Many studies offer theoretical explanations of caregiver outcomes based on the Transactional model of Stress and Coping (TSC; Lazarus and Folkman, 1984) where coping is defined as a process of "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands… appraised as taxing or exceeding [personal] resources" (p.141). Inherent in this process are coping responses, typically problem-focussed ("actions that change the…relationship between the person and the environment"), emotion-focussed ("actions that [change] the meaning of that relationship" such as avoidance, distraction and minimisation) or cognitive (influencing stress and emotion by "re-appraisal of the person-environment relationship") (Lazarus and Folkman, p.77; 1984). Haley et al., (1987) reported that appraisal and coping responses were significant predictors of outcomes in adult dementia caregivers. This has been further demonstrated where caregiving factors, cognitive appraisal, coping strategies and coping resources were predictors of adjustment in adult multiple sclerosis (MS) carers (K. I. Pakenham, 2001).

Use of problem-focussed coping is associated with better caregiver adjustment than emotion-focussed coping (Pakenham, 2001). Branscum (Branscum, 2010) suggests that adverse caregiving effects in adults can be lessened with adequate social support and problem-focused coping. Yet defining psychological concepts such as coping and adjustment is challenging in any population and the TSC model has been criticised for its oversimplification and disregard of the situational nature of coping (Schwarzer & Schwarzer, 1996). Others have incorporated multi-dimensional approaches and highlight the effectiveness of strategies may vary depending on the situation and stressor encountered (Carver et al., 1989). Similarly, Skinner (2007) proposed twelve 'families' of coping based on function and contribution to adaptation. At a physiological level, the concepts of allostasis and allostatic load are a well-accepted explanation for adjustment in underlying mechanisms resulting in differential health outcomes (McEwen, 1998; Sterling & Eyer, 1988). These concepts have been applied to a model of adjustment in investigating the physical impact of caregiving (Vedhara et al., 1999; Vedhara et al., 2002).

Whilst empirical studies have considered factors associated with adjustment and coping in the caregiving population, reviews conducted in this area predominantly describe or collate findings assessing the needs of caregivers, providing data on prevalence and impact. The literature has not been systematically reviewed to draw conclusions about the factors associated with coping behaviours. Reviews that have considered coping and adjustment in caregivers are now outdated (Low et al., 1999) or focus on specific caregiving populations (e.g. stroke caregivers, del-Pino-Casado et al., 2011).

The aim of this study was to assess coping and adjustment across all caregiver ages and conditions cared for, using a systematic review. Identifying coping factors associated with adjustment or stress resilience can inform future research and health providers aiming to support carers.

Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, see supplemental material) guidelines were used (Moher, D; Liberati, A; Tetzlaff & Altman, 2010).

Search strategy

Four online databases (PsychNET, Web of Science, Pubmed and Scopus) were searched.

References of retrieved papers, previous reviews and books were scanned. Experts in the area were consulted via email where appropriate. A search of cited reference lists was also carried out. Figure 1 details the search process.

Searches were conducted (05/11/2015, repeated 09/10/2017 and 07/01/2018) using key words (coping, adjustment, outcomes and caregivers) and Boolean operators. Some search terms differed between databases due to the availability of index terms and database specific filters (e.g. PsycNet search: Coping behaviour AND Adjustment OR Outcomes AND caregiv* NOT intervention. Web of Science search: Coping AND Adjustment OR Outcomes AND "Family caregivers" NOT intervention*).

There were no publication date limits. Both quantitative and qualitative studies were reviewed.

INSERT FIGURE 1 ABOUT HERE

Study Selection

Duplicates were removed and results were reviewed based on titles and abstracts. Full texts were retrieved for eligible studies and further reviewed for inclusion and exclusion criteria. Data were extracted from articles using a piloted data extraction form that included information about aims, design, sample, measures and findings.

Inclusion and exclusion criteria

Inclusion criteria for quantitative studies were that they: (1) reported experiences of informal caregivers; (2) investigated chronic stress (a stressor that is gradual, long-term and continuous (Wheaton, 1997)); (3) measured coping and/or outcomes; and (4) included a control or comparison group. Inclusion criteria for qualitative studies were that they: (1) reported the experiences of informal caregivers; (2) investigated chronic stress; and (3) discussed coping style/strategies and outcomes. A control or comparison group was required for quantitative studies to reflect methodological quality, but was not required for qualitative studies.

Studies were therefore excluded if they: (1) Were not the target population or topic (e.g. animal studies, formal caregivers or did not investigate coping; (2) were a previous systematic review; (3) were an intervention based study; (4) were not written in English and a translation was not available; (5) were a scale development study; (6) investigated acute stress or (7) did not have a control group (for quantitative studies).

Two reviewers assessed articles against criteria; checking and confirmation was conducted by the second reviewer and disagreements were resolved through discussion.

Quality Ratings

All selected studies were subjected to quality appraisal. Quantitative studies were rated for quality across four dimensions; sample; attrition; measurement; and analysis using 11 criteria developed by Laisné, Lecomte, and Corbière (2012). Studies were rated zero (no; partial) and one (yes), therefore the maximum score was 11. All studies reached moderate (>5) to high quality (>8); none were excluded.

Qualitative studies were rated using Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004). Ten criteria were used to assess design, sampling, data collection and analysis and were rated zero (no), one (partial) and two (yes); maximum score was 20. All qualitative studies were rated as high (>15).

Results

A total of 27 empirical papers met inclusion criteria; 13 used a quantitative and 14 used a qualitative methodology (see Tables 1-2 supplemental material). Publication years ranged

from 1996 to 2015. All quantitative studies used self-report measures to collect data and were predominantly cross-sectional. One study was longitudinal (with a control group). All of the quantitative studies used a between-groups design (e.g. caregiver vs non-caregiver, dementia caregiver vs stroke caregiver). Controls and comparison groups comprised of non-caregivers, caregivers of healthy individuals, or caregivers of a comparison health condition. Qualitative data in all 14 studies were collected via semi-structured interview, with one study also using photo elicitation and another using observation. Qualitative analysis was mostly thematic, alongside interpretive phenomenological analysis, content analysis and grounded theory. One qualitative study was longitudinal and presented as a case study.

A total of 2084 participants were included, with a minimum of one participant and a maximum of 246. The minimum mean age was 17 years; maximum 74 years. Care provided was in the context of a range of health conditions as indicated in Table 1 and caregivers were related to care recipients as grandparents, spouses, parents and offspring.

Table 1. Health conditions and contexts of individuals cared for by caregivers

INSERT TABLE 1 HERE

Findings from the 27 papers were synthesised using thematic analysis (Braun & Clarke, 2006). Substantive insights were identified in four areas: i) problem versus emotion-focussed coping; ii) use of cognitive strategies; iii) factors associated with psychological adjustment; and iv) factors associated with physiological adjustment. There were also clear methodological issues.

Use of problem versus emotion-focussed coping

The studies in this review identified a number of coping strategies utilised by participants, categorised as problem or emotion-focussed coping, in line with the definitions above.

Caregivers reported using fewer positive strategies and relied less on problem-focussed coping than non-caregivers (Mausbach et al., 2013; Kenneth I Pakenham & Bursnall, 2006). Some studies investigated the relationship between coping styles and adjustment. Mausbach et al. (2013) identified that carers using fewer positive strategies (e.g. engaging in pleasant activities, seeking social support) and greater negative coping strategies (e.g. self-blame, avoidance), reported poorer psychosocial outcomes and adjustment compared to non-caregivers. Negative impacts included increased depressive symptoms, negative affect, fear, hostility and sadness.

Problem-focussed coping was generally considered most adaptive and associated with less psychological distress and more positive outcomes (Bachanas et al., 2001; Kenneth I Pakenham & Bursnall, 2006). Ten studies reported examples of problem-focused strategies adopted by caregivers. Some of these strategies were actions the caregiver took to reduce their burden, (reducing work hours, using paid carers, accepting financial hardship, integrating care into family culture, daily routines, incorporating risk management into daily life, utilising social support and effectively planning activities and care; Dickson et al., 2012; Kita and Ito, 2013; McCausland Kurz and Cavanaugh, 2001; Sun, 2014; Williams et al., 2014). Other problem-focussed coping involved action or changes in behaviour surrounding the cared for person to reduce time and labour (e.g. coping with their physical limitations, engaging them in activities, lowering expectations of them, avoiding confrontation, finding humour, overseeing health and treatments and modifying communication methods. Finally, problem-focussed strategies included communicating with others and researching the health condition to increase a sense of control (Williams et al., 2014). Caregivers reported comparing their relative's health through books and social media: communicating with schools and others in similar situations through online platforms or support groups and researching online about the cared for person's condition (Le Dorze et al., 2009; McCausland Kurz & Cavanaugh, 2001; Sun, 2014; Williams et al., 2014). Although problem-focussed strategies were generally reported as most helpful and associated with more positive outcomes in caregivers, in many cases these were not used more than emotion-focussed strategies.

Overall, studies that reported use of emotion-focussed coping strategies found associations with negative outcomes, with caregivers being less able to regulate their negative emotions compared to controls (Ruiz-Robledillo & Moya-Albiol, 2013). Figueiredo and colleagues (2014) found that greater use of emotional coping was associated with poorer mental health perception. Sander, High, Hannay, and Sherer (1997) report associations between greater use of emotion-focussed coping and levels of psychological and emotional distress. Others specify emotion-focussed techniques such as distraction and avoidance as being considered unhelpful by caregivers. Haley and colleagues (1996) reported that high levels of avoidance coping and low levels of approach coping were associated with greater depression and decreased life satisfaction. Wishful thinking and denial, were also found to be related to greater psychological distress (Kenneth I Pakenham & Bursnall, 2006). Despite the generally reported negative impact of emotion-focussed coping, there were some exceptions where carers felt these strategies were helpful, including venting emotion, taking time out, and having a 'good cry' to release emotional energy (Azman et al., 2017; Dickson et al., 2012; Figueiredo et al., 2014).

The quantitative longitudinal study examined use of problem and emotion-focussed coping in mothers caring for an adult child with an intellectual disability or mental health condition (H. W. Kim et al., 2003). Higher initial and increased use of problem-focussed coping predicted declining levels of burden and depressive symptoms. More use of emotion-focussed strategies increased burden and depressive symptoms and contributed to poorer parent-child relations.

Finally, three papers reported the use of religious coping, whereby caregivers described a strong faith or spirituality enabling them to cope with their caregiving responsibilities; having strong religious convictions enabled better stress management (Azman et al., 2017). Church services were a source of social support and seeking advice from a pastor was also valued (Gerdner et al., 2007). Attending church services and upholding religious practices and values allowed caregivers to maintain a life separate from caregiving, which they considered important (Thornton & Hopp, 2011).

Use of cognitive strategies

Cognitive coping strategies were identified in six papers. These strategies involved a conscious effort to alter perceptions, appraisals or cognitions surrounding caregiving to promote a greater sense of well-being. Unlike problem or emotion-focused coping, cognitive strategies are not behavioural and are defined as thoughts used to deal with stressful or challenging situations which typically involve the mental perception an individual has surrounding their ability to manage a stressor (Lazarus & Folkman, 1984). Most reported was the use of acceptance. This involved acceptance of inequalities surrounding caregiving and the individual being caring for, as well as accepting that the situation was unchangeable and that life could never be the same again (Azman et al., 2017; Dickson et al., 2012; McCausland Kurz & Cavanaugh, 2001; Williams et al., 2014; Zegwaard et al., 2013). Appraisal was highlighted as an important factor. Haley et al. (1996) found that the effects of stressors were mediated by the appraisal caregivers had of their experiences, and Pakenham and Bursnall (2006) reported that higher stress appraisals were related to higher distress and lower life satisfaction in caregivers.

Social comparisons were also used by caregivers, including comparing their current situation to another difficult situation in their past, such as the illness or death of parents (McCausland Kurz & Cavanaugh, 2001). Additionally, caregivers reported making downward comparisons to others in similar circumstances, as well as considering themselves more fortunate and comparing their resources to others to feel efficient and capable (Williams et al., 2014).

Some cognitive strategies involved perceptions of the caregiver role and caregivers reported that valuing their role, retaining autonomy, identifying benefits and finding meaning in their experiences, helped them adjust to their situation (Kitter & Sharman, 2015; Thornton & Hopp, 2011; Zegwaard et al., 2013). Reframing aspects of their experience enabled effective coping and involved looking on the bright side; finding humour when feeling helpless and reframing perceptions positively (Bailey et al., 2013; Williams et al., 2014). In particular, taking a gain rather than a loss mentality was deemed helpful by those who chose to perceive their caregiving as a choice and voluntary act of compassion, rather than as a forced obligation (Zegwaard et al., 2013).

Factors associated with psychological adjustment

A number of factors associated with psychological adjustment were identified. Social support was frequently correlated with positive adjustment. High levels of social support correlated with higher positive outcomes, less distress and better health in caregivers (William E. Haley et al., 1996; Kenneth I Pakenham & Bursnall, 2006). Wong et al. (2015) found a strong, positive marital bond, affection and feeling cared for were supportive of good adjustment in caregivers. Consistent positive social interaction which enabled individuals to feel supported in terms of their emotions and self-esteem was also deemed important for adjustment and promoted resilience (Kaplan, 2010; McCausland Kurz & Cavanaugh, 2001; Ruiz-Robledillo et al., 2014). Specifically, caregivers noted that opportunities to share information and their experiences within their social network positively influenced their adjustment and outcomes (Kita & Ito, 2013; McCausland Kurz & Cavanaugh, 2001). Social support also took the form of practical support and was associated with adjustment (McCausland Kurz & Cavanaugh, 2001). Practical support in the form of physical care often came from friends or family members, such as adult children (Gerdner et al., 2007; Kaplan, 2010). Tangible support was also sought in a more formal manner from professional services such as adult day care or home health services, and was positively associated with adjustment (Gerdner et al., 2007).

Factors associated with poorer adjustment were identified in two studies. Bachanas et al. (2001) found a greater number of daily hassles, use of emotion-focussed coping and fewer family resources, were related to poorer adjustment. Pakenham and Bursnall (2006) established that lower levels of perceived choice in caregiving were associated with lower adjustment on measures such as life satisfaction, benefit finding and positive affect.

Factors associated with physiological adjustment

Only six studies reported findings regarding physiological adjustment, five of which measured self-reported physical health to determine health status. Two studies found that caregivers endorsed more symptoms using physical health measures and worse health than controls (Mccallum et al., 2003; Ruiz-Robledillo & Moya-Albiol, 2013). Some studies reported specific factors positively associated with better self-reported health in caregivers and these included increased use of problem-solving coping and higher resilience (Figueiredo et al., 2014; Ruiz-Robledillo et al., 2014). Other studies reported factors that were negatively associated with self-reported health. Ruiz-Robledillo and Moya-Albiol (2013) found that higher trait anxiety, greater cognitive-oriented problem coping and higher levels of burden were associated with poorer health in caregivers. However, Kim and Knight (Kim & Knight, 2008) found that coping was not associated with the impact of caregiving upon health outcomes.

In addition to self-report measures, four papers used biomarkers of stress in the form of blood pressure and salivary cortisol. Studies assessing cortisol have generally found support for caregiving as a stressor associated with increases in cortisol levels and disruption of the diurnal decrease or awakening response. Higher cortisol and blood pressure were reported in caregivers compared to non-caregivers (J. H. Kim & Knight, 2008; Ruiz-Robledillo & Moya-Albiol, 2013). Kim and Knight (J. H. Kim & Knight, 2008) reported that lower instrumental social support was associated with higher levels of salivary cortisol, and Ruiz-Robledillo et al. (2014) found that resilience was negatively correlated with caregivers' cortisol awakening response (CAR) and also reported lower total salivary cortisol concentration, as assessed by a smaller area under the curve, over the sampling period. However, Merritt and McCallum (2013) found that greater use of positive religious coping correlated with a flatter cortisol decline across the day for African-American (AA) caregivers coping with behavioural problems in family members with dementia compared to non-caregivers, suggesting that AA caregivers require a wider range of religious coping skills that incorporates both positive and negative religious coping.

Methodological considerations

In this systematic review, a number of methodological issues were evident. Since evidence shows that caregiving can significantly impact the psychosocial and physical health of individuals, it was surprising that 23 papers assessed only psychosocial factors; most particularly, coping strategies, coping resources, social adjustment, stress appraisal and positive and negative affect. Only four studies utilised physiological measures notably blood pressure

and salivary cortisol. Eight studies used self-reported physical health and symptom inventory checklists. Reviews of method sections found a wide variety of measures were employed, approximately 60 different scales and measures. Of these, eight were caregiver specific.

Although 15 studies referred to theory, 12 did not. Of the 13 quantitative studies, 9 referred to theory, most commonly the TSC (Lazarus & Folkman, 1984) and the Sociocultural Stress and Coping Model for Caregivers (Aranda & Knight, 1997). In some instances these theories guided research and were tested, but in others were provided to explain findings. Of the 14 qualitative studies, 6 referenced theory, most often the ABCX Model of Family Adaptation (McCubbin & Patterson, 1983) and Stress Coping Frameworks (Knight et al., 2000; Lazarus & Folkman, 1984).

Only 2 of the 27 studies were longitudinal. The first, a quantitative study (H. W. Kim et al., 2003) provided predictive data regarding problem and emotion-focussed coping in mothers caring for an adult child. The second, a seven-month qualitative case study (Le Dorze et al., 2009) observed adjustment of a daughter whose father had aphasia and had suffered a stroke.

Finally, much of the caregiver literature has focussed on older adults, with some investigating younger adults, very few explore coping and adjustment in young carers. Of the 27 studies, 23 reported the mean age of the caregivers; in 22 of these studies it ranged from 25 to 74 years. Only one study reported a mean caregiver age that would be considered a young carer population; ages ranged from 10-25 years (mean age 17 years).

Discussion

Through this systematic review of quantitative and qualitative literature, a number of coping factors associated with adjustment in caregivers were identified.

Summary of findings

Problem-focussed coping as a method for adjusting to the role and responsibilities of caregiving was associated with more positive adjustment and outcomes. Emotion-focussed coping was associated negatively with caregiver adjustment and linked to increased psychological and emotional distress. Despite this general finding, some subjective reports in qualitative data identified helpful emotion-focused techniques. This highlights the dynamic and changing nature of coping, and the importance of taking into account individual circumstances. Previous research has found that strategies cannot necessarily be categorised into positive or negative approaches, and that some stressors, such as those that cannot be changed by way of problem-focussed approaches, benefit most from emotion-focussed techniques (Lazarus & Folkman, 1984). Unfortunately, the literature in this review does not offer information regarding the fit between the stressor and a chosen coping strategy in caregivers. This warrants investigation.

In addition to problem and emotion-focused strategies a number of cognitive strategies were identified. Whilst cognitive factors can be viewed as independent of problem and emotion-focussed coping, it is important to acknowledge that the three strategy styles cannot always be viewed separately. The associations between different coping styles identified in this review support the findings of previous research demonstrating that a combination of problem-focussed, emotion-focussed and cognitive strategies is often the most effective way to cope with stressors (K. I. Pakenham, 2001). The studies in this review do not provide insight regarding the balance between coping approaches or the number of unique strategies employed.

Ten papers in the review identified factors associated with poor adjustment (three studies) and positive adjustment (seven studies). The factor most frequently positively correlated with adjustment was social support in the form of emotional and physical, tangible assistance. Caregivers highlighted that sharing their experiences and information with other carers was useful, confirming the protective nature of social support against social judgement and perceived stress (Beck, 2007).

Although only six of the papers reported physiological adjustment in caregivers, some common findings were identified. Overall this review supports previous findings that caregiving is associated with elevated cortisol levels and subjective reports of poorer health compared to non-caregivers. Since the immune system naturally deteriorates with age (termed immunosenescence), the impact of stress may be greater or more pronounced in older individuals (Kavita Vedhara et al., 2002). As such, findings from adult and elderly caregivers

may not represent young carers, who potentially have a more optimum immune system. The mean age of participants in the six studies reporting physical health outcomes was 55.5 years. The caregiver literature would benefit from further research surrounding physiological outcomes across all age groups to adequately disaggregate the physiological effects on immune functioning by age. It is evident from this review that it is important to extend research using physiological markers, such as salivary cortisol, to young caregivers. To our knowledge this has not yet been conducted and could provide an indication of the effects of caregiving across the lifespan. This is supported by Barnett & Parker's (1998) assertion that although a great deal of research has been conducted with adult caregivers, the same cannot be said for young caregivers. In particular, Simon and Slatcher (2011) note that little is known about the physical health of child caregivers compared to adults. This review highlights this limitation.

Methodological considerations and limitations of the review literature

Numerous methodological considerations regarding the studies in this review were identified. During data extraction it was evident that a variety of quantitative measures were employed to assess aspects of caregiving; there were very few designed specifically for caregivers. An important question to address is whether tailor-made measures for caregivers would be useful to assess factors such as burden and stress in this unique population. Furthermore, a more consistent use of measures across studies would increase their comparative value and enable meta-analyses to be conducted.

Regarding outcome measures, only 6 studies took a biopsychosocial approach, measuring physical health through either self-report or physiological measurement. The remaining 21 studies measured purely psychosocial factors and did not consider physical outcomes. Assessment of physiological outcomes in the adjustment of caregivers however, is gaining interest, as shown by the more recent studies reviewed; we would call for such assessments receiving greater attention.

There is limited focus on young carers, with only one study investigating this population. The most recent UK census reported 177,918 young carers between five and 17 years old, however this is believed to be a gross underrepresentation. Though research has identified the potential negative impact of early caregiving (Thomas et al., 2003) not all young carers or children living with ill parents demonstrate these outcomes. In fact, some show evidence of resilience, particularly physiologically (Turner et al., 1998). It is imperative that future research investigates this population to determine resilience factors. The TSC (Lazarus & Folkman, 1984) which many studies refer to, describes a dynamic process, capable of changing and developing over time. Exposure to caregiving at a young age may impact adulthood and longitudinal study of caregivers at various points in their life would allow the process of coping to be observed over time and investigation of the temporal demands of caregiving.

A call for greater longitudinal research in caregiver coping is further supported by the majority of quantitative studies in this review being of cross-sectional design and offering little predictive value to assess the direct impact of specific coping strategies on adjustment. Whilst cross-sectional studies have provided insight in this relatively new field, progression towards longitudinal assessment with the power to predict the effect of coping strategies upon adjustment is needed.

Strengths of the review literature

Despite the numerous limitations noted within the papers there are strengths. Firstly, all studies, when subjected to quality appraisal were deemed sufficient in quality to be included in the study, suggesting research in this area is being conducted rigorously. Secondly, although some studies reported the negative impact of caregiving and factors associated with poor adjustment, many studies took a resiliency approach, focusing on coping factors positively associated with adjustment. Future development of interventions designed to help caregivers cope effectively can be enhanced by inclusion of such factors.

Limitations of the review

This systematic review has limitations. Firstly, due to language barriers, papers not written in English were excluded. Despite this, the included studies were carried out in a range of countries, including the UK, USA, Portugal and Korea (Bachanas et al., 2001; Barbosa et al.,

2011; Dickson et al., 2012; Kim & Knight, 2008) reducing the likelihood of cultural bias. Secondly, only published papers were included, this was to ensure a level of quality subject to peer-review. As such it is possible that we introduced a bias by not representing studies with unexpected or non-significant findings. However, the inclusion of qualitative literature, with sufficient quality ratings, that do not require statistical analysis or significance ensures a variety of findings were reported. Furthermore, this review used the terms 'carer' and 'caregiver' when searching, which poses a possible issue as these terms are relatively new in the literature. Early work used descriptive terms (e.g. spouses of individuals with an illness or children living with parental illness) rather than identifying individuals as caregivers per se (Folkman et al., 1997; Westbom, 1992). It is possible that use of these terms resulted in the exclusion of relevant literature. Finally, though the term adjustment was chosen for use in this review due to its encompassing nature with regard to outcomes and coping, it is possible that not deconstructing this term and focusing on specific aspects of adjustment may also have limited the literature found when searching.

Conclusion

This study reviewed the literature surrounding coping and adjustment in caregivers across all ages, to identify outcomes associated with caregiving and to contribute to this developing area of research by identifying coping factors associated with adjustment.

This review found that problem-focused coping is associated with more positive adjustment than emotion-focused coping. Cognitive strategies (e.g. acceptance, appraisal) were positively related to adjustment, as well as social support, particularly with regard to physiological outcomes. Given these findings, those seeking to provide caregiver support may consider harnessing these factors, for example, developing coping skills and social support networks.

Methodological issues were identified which highlight considerable gaps within the literature and present a strong call for research that seeks to (1) address the imbalance between studies using purely psychosocial measures and the few using physiological measures to develop a deeper understanding regarding the physiological impact of caregiving; (2) develop longitudinal studies to provide predictive data and (3) investigate young carers to assess the impact of caregiving across the lifespan. Beyond this review, further meta-analytic examination of findings in this field is warranted and called for.

To develop appropriate interventions for a growing caregiver population, a clear and coherent understanding of the mechanisms underlying coping, adjustment, vulnerability and resilience in operation is needed. This systematic review highlights the importance of such work and draws attention to the gaps in caregiver research across different age groups, as well as the need for a more coherent understanding of consistencies and discrepancies in caregiver outcomes at different points across the lifespan.

Conflicts of interest

The authors declare that they have no competing interests

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Note: *indicates included as one of the 27 papers in the systematic review reported

Appendix B: PRISMA Checklist (Study one)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1, 2, 3
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	7
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7-8

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	8-9
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I_2) for each meta-analysis.	N/A
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	8-9
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8-9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A

DISCUSSION	
Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	19-24, 26-28
Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	27-28
Provide a general interpretation of the results in the context of other evidence, and implications for future research.	26
FUNDING	
Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	1

Note. Pages correspond to pages of the manuscript submitted for publication

Appendix C: Main characteristics of studies included in the systematic review (study one)

Table 1. Characteristics of quantitative studies

Study	Quality score (max 11)	Method	Participant characteristics	Theory	Psycho- social measures	Physio- logical measures	Findings
Bachanas et al (2001)	5	Cross- sectional Self-report Between groups	n= 36 CG's, 32 matched control NCG's	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	✓		Poor CG adjustment related to more daily hassles, use of more palliative coping strategies and fewer family resources CG's who report more daily hassles report more psychological distress CG's using more palliative coping reported more psychological distress than CG's using more adaptive coping
Barbosa, Figueired, Sousa & Demain (2011)	7	Cross- sectional Self-report Between groups	n= 90 primary CG's, 90 secondary CG's Mean age 45.23 years	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	✓		All strategies involving direct action were used and perceived as helpful by more than 50% of CG's Relying on own expertise and experience was most useful approach for both groups Planning in advance most useful and effective for secondary CG's Primary CG's used firmness, pointing out expectations, preventing problems, getting professional help and altering home environment Believing in oneself and one's ability to handle the situation were most successful emotional-cognitive strategies
Figueiredo et al (2014)	8	Cross- sectional Self-report Between groups	n= 158 family CG's Mean age 58.39 years		✓		Increased use of problem solving coping associated with better self-rated physical health Higher use of emotional-cognitive coping and dealing with the consequences of stress were associated with poorer mental health perception Secondary CG's found distraction and avoidance strategies less effective Have a good cry useful for primary CG's and get rid of excess energy for secondary CG's

Haley et al (1996)	6	Cross- sectional Self-report Between groups	n= 123 white CG's, 74 black CG's Mean age 62.36/55.45 years	Stress Process Model (Haley, Levine, Brown & Bartolucci, 1987)	✓		Effects of stressors mediated by social support, coping and appraisals High levels of avoidance coping and low levels of approach coping were related to increased depression and lower life satisfaction Greater social support and activity related to higher life satisfaction and lower depression High stress appraisals associated with higher depression
Kim, Greenberg, Seltzer & Krauss (2003)	7	Longitudinal Self-report Between groups	n= 246 mothers of adults with intellectual disability, 74 mothers of adults with mental illness Mean age 66 years	Stress and Coping paradigm (Pearlin et al, 1990)	✓		Higher initial and increased use of problem focussed (PF) coping in mothers of ID predicted declining levels of burden Increased emotion focussed (EF) coping in mothers of ID increased burden, decreased EF coping decreased burden High use of PF coping and low use of EF coping at wave 1 predicted declining depressive symptoms Increase of EF coping between waves 1 and 2 related to higher burden and depression and poorer relationship with the child Mothers of ID increased in PF coping over time, leading to lower subjective burden and depression and better relationships at wave 2
Kim & Knight (2008)	7	Cross- sectional Self-report Between groups	n= 87 CG's, 87 matched NCG's Mean age 63 years	Sociocultural stress and coping model for caregivers (Aranda & knight 1997)	✓	✓ Blood pressure Salivary cortisol	Being a CG significantly associated with higher levels of BP and cortisol Lower instrumental social support – higher levels of cortisol
Mausbach, Chattillion, Roepke, Patterson & Grant (2013)	6	Cross- sectional Self-report Between groups	n= 125 CG's of spouses with Alzheimer's Disease (AD), 60 spouses not caring for AD		✓		CG had greater depressive symptoms than controls, higher NA, fear, hostility and sadness CG more likely to report less PA and joviality relative to controls Lower access to several psychological resources relative to controls CG reported greater activity restriction than NC Caregivers utilised fewer positive coping and greater negative coping strategies relative to controls

McCallum, Longmire & Knight (2007)	**5**	Cross- sectional Self-report Between groups	n= 35 African American (AA) CG's, 35 White American CG's Mean age 60.73/65.42 years	Sociocultural stress and coping model (Aranda & knight 1997)	✓		Active and avoidant coping scores were similar between groups Did not differ in terms of burden or depressive symptoms Subjective reports of poor physical health higher in AA CG's
Merritt & McCallum (2013)	6	Cross- sectional Self-report Between groups	n= 30 CG's, 30 NCG's Mean age 58.2/59.6		✓	✓ Salivary cortisol	Higher positive RCOPE & higher cortisol slopes correlated Increased RCOPE scores associated with flatter cort slope Caregiver status associated with marginally flatter but non-significant cortisol slopes than non-caregivers Higher RCOPE scores were correlated with flatter cortisol slopes for caregivers but not for non-caregivers Positive RCOPE associated with flatter cortisol slope Higher negative RCOPE predicted marginally flatter negative cortisol slopes for non-caregivers, not caregivers Higher combined and positive (but not negative) RCOPE scores were associated with increasingly flatter or worse cortisol slope scores for caregivers (but not controls) Caregivers with higher RMBPC scores, higher combined and positive (not negative) RCOPE scores were unexpectedly associated with increased flatter cort slopes
Pakenham & Bursnall (2006)	6	Cross- sectional Self-report Between groups	n= 48 children of parents with MS, 146 children with health parent mean age 17.7 years	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	✓		Parental illness and greater family responsibilities related to higher distress Lower levels of perceived choice in caregiving and parental functional impairment associated with lower adjustment on positive outcomes Higher stress appraisals related to higher distress and lower life satisfaction Higher levels of qualitative social support related to higher positive outcomes, less distress and better health, greater number of support people was related to greater life satisfaction More reliance on problem solving, acceptance and seeking social support and less reliance on wishful thinking and denial = greater positive outcomes Greater reliance on wishful thinking and denial related to greater distress MS caregivers reported higher family responsibilities and somatization, lower life satisfaction and positive affect and less reliance on problem solving coping and seeking social support coping None of the coping strategies were related to health status

Ruiz-Robledillo & Moya-Albiol (2013)	**7**	Cross- sectional Self-report Between groups	n= 53 parents of child with Autism Spectrum Disorder (ASD), 54 parents of health children Mean age 45.32/42.80		✓	✓ Salivary cortisol	Caregivers used 'behaviour escape' more than controls Caregivers showed lower social support in all dimensions Caregivers showed higher levels of trait anxiety, depressive symptoms, internal/external anger expression Caregivers showed less ability to regulate negative emotions compared to the control group Caregivers indicated more symptoms on all physical health subscales indicating poorer health Higher magnitude of cortisol response in caregivers than the controls when controlling for negative effect
Ruiz-Robledillo et al (2014)	7	Cross- sectional Self-report Between groups	n= 67 parents of ASD Mean age 45.46 years		✓	✓ Salivary cortisol	Resilience negatively correlated with somatic symptoms, anxiety, insomnia, perceived general health, four time points of cortisol and AUC High resilience related to high levels of emotional, tangible, positive social interaction & global index of support When controlling for CG variables – no significant associations between resilience, somatic symptoms and severe depression – relationship between resilience and perceived general health remained significant Total effect of resilience on perceived general health was significant, resilience in turn predicted social support – social support predicted perceived general health Emotional/informational support and positive social interaction had direct effects on perceived general health CG's with higher resilience show better perceived health, lower morning cortisol levels and less AUC
Sander, High, Hannay & Sherer (1997)	7	Cross- sectional Self-report Between groups	n= 69 CG of close head injury (acute, intermediate and long term) Mean age 39.1/45.8/45.1 years	Framework for studying family stress following TBI (Graffi & Mines)	✓		As emotion-focused coping increased so did level of psychological distress Coping did not moderate relationship between burden and emotional distress Satisfaction with social support linked to psychological distress Greater use of emotion-focussed coping was related to greater emotional distress – coping style contributed to variance in BHQ scores Problem-focused coping not related to GHQ scores Coping accounted for more of the variance in BHQ scores than DRS scores Higher levels of subjective burden were related to greater number of symptoms on GHQ Amount of social support was not related to GHQ

Table 2. Characteristics of qualitative studies

Study	Quality Score (Max 20)	Method	Participant characteristics	Theory	Findings
Azman et al (2015)	17	Semi-structured interviews Content analysis	N=15, CG's of mental ill family members, age 25-86,		Five coping strategies identified: 1. Religious coping 2. Emotional coping 3. Acceptance 4. Engage in leisure activities 5. Traditional healing
Bailey, Letiecq & Porterfield (2009)	19	Semi-structured interviews Thematic Analysis	n= 26 grand families	Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983)	Communicating with schools Reframing perceptions as positive
Dickson et al (2011)	16	Semi-structured interviews Interpretive Phenomenological Analysis	n= 11 spousal CG's of acquired traumatic Spinal Cord Injury		Coping with the spousal caregiver role (emotion focussed strategies): venting emotion, time out, role of support, focussing on the positive aspects of SCI Putting the pieces back together again: reducing work hours, accepting financial hardship, using paid carers, acceptance that life will never be the same, balance between adaptability and stability, positive reappraisal
Gerdner, Tripp-Reimer & Simpson (2007)	18	Longitudinal Semi-structured interviews Observation Ethnographic analysis	n= 15 African American CG's		Need for patience Support with physical care Emotional support from family members & ministers Spirituality – strong religious convictions, church services Formal assistance – adult day care, home health services
Kaplan (2010)	14	Semi-structured interviews Grounded Theory	n= 20 CG mothers		Consistent social support – friend or family member that helps with care Uncertain future affected coping and structural barriers like lack of communication
Kita & Ito (2013)	19	Semi-structured interviews Comparative Analysis/ Grounded Theory	n= 18 family CG's of frail older adults	Family Systems Theory (Bowen, 1966)	Routinisation of daily life Minimisation of competition of needs among family members Incorporate risk management strategies into daily life Integrate care methods and outside services into family culture Reconfirming the meaning and importance of the care Sharing care experiences Devising care methods to reduce time and labour

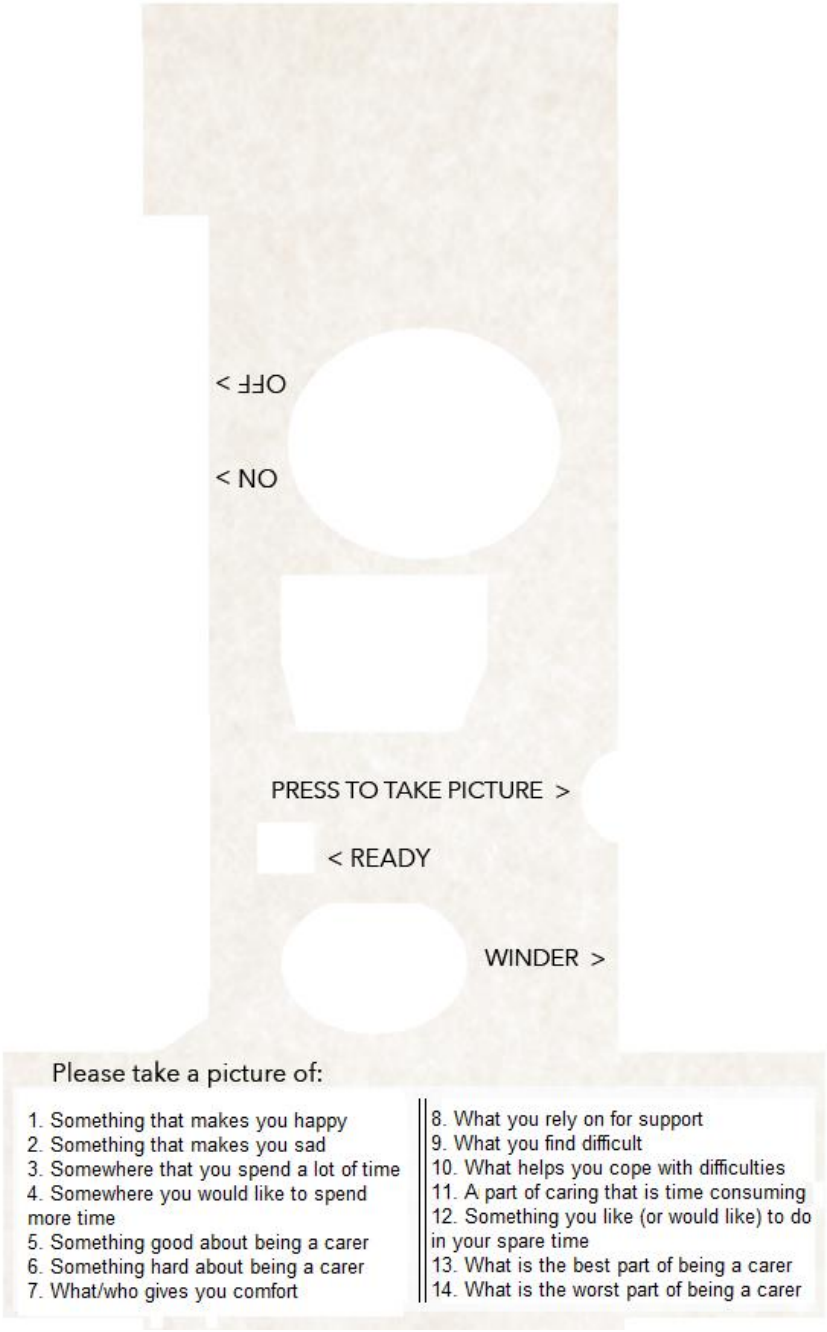
Kitter & Sharman (2015)	19	Semi-structured interviews	n= 20 CG's of traumatic brain injury	Self-determination theory	Social support was beneficial – good to talk Enriching experiences through caregiving – appreciation of life Keeping own identity Taking time out/respite
Le Dorze, Tremblay & Croteau (2009)	19	Semi-structured interviews	n= 1 adult daughter CG for aphasic father	Adaptation theory (Michallet et al 2003)	Reaction to stress was proactive: obtained information, modified communication with father and oversaw his health and treatments Used visual supports, proximity to father, communicating with others in a similar situation, self-care
McCausland & Cavanaugh (2001)	19	Semi-structured interviews Comparative method	n= 13 CG of spouses waiting for lung transplant		Social support, drawing on past experience of illnesses or deaths of parents Action: calling social support, support groups, researching online, volunteering, and therapy. Acceptance: recognition that undesirable situation could not be changed Disengagement: separation from the transplant situation – e.g. guests, working Planning: Child care, work arrangements, packing bags, telephone calls, living will. Support: emotional, esteem, information sharing, tangible support
Sun (2014)	20	Semi-structured interviews Thematic Analysis	n= 18 family CG of dementia	Stress-coping frameworks (Knight et al 2000, Lazarus and Folkman 1984)	EFC – to cope with worries, frustration and other negative feelings associated with CG. Hobbies, self-validation, informal support, counselling. PFC – compare progress with books & media Coping with physical limitations and emotional/behavioural problems of CR – physical exercise, indoor games, paid homemakers, engage in activities, lowering expectations, avoid confrontation, finding humour, technology Coping with social restrictions – find alternative entertainment than leaving house, computer games, reading Coping with financial burden – PFC seeking employment and assistance from government PFC – for family conflict Coping with pressure from social environment – withhold information Seeking an explanation, finding meaning
Thornton & Hopp (2011)	18	Semi-structured interviews Interpretive Phenomenological Analysis	n= 7 adult daughter CG's		Valuing the caregiver role, identifying benefits, recognition Coordination of care with siblings – consistent communication and effort Taking charge – initiative, decisiveness and readiness to take on the role, housing arrangements, leadership within family Spirituality – religion, social support

Williams, Morrison & Robinson (2014)	19	Semi-structured interviews Photo elicitation Interpretive Phenomenological Analysis	n= 13 CG's of stroke or dementia	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	Looking on the bright side Downward comparisons with others – considering themselves more fortunate, and coping resources as more efficient Humour when feeling helpless Acceptance- adopting innovative coping techniques Normalising problems Planning, organising and seeking information to increase sense of control Some avoidant coping behaviours
Wong et al (2015)	19	Semi-structured interviews Grounded Theory	n= 10 CG families of dementia		Positive marital bond was a coping strategy, affection, physical touch, feeling cared for Support from adult children
Zegwaard et al (2013)	19	Semi-structured interviews Associative, inductive strategy and continuous coding	n= 19 CG who look after older adults with severe mental illness		Perceived freedom of choice – voluntary act of compassion vs unavoidable obligation, gain vs loss Togetherness, accepting inequality, autonomy Finding meaning, meaningful participation in social life Acceptance

Appendix D: List of photo prompts (Study two)

1. Something that makes you happy
2. Something that makes you sad
3. Somewhere that you spend a lot of time
4. Somewhere you would like to spend more time
5. Something good about being a carer
6. Something hard about being a carer
7. What/who gives you comfort
8. What you rely on for support
9. What you find difficult
10. What helps you cope with difficulties
11. A part of caring that is time consuming
12. Something you like (or would like) to do in your spare time
13. What is the best part of being a carer
14. What is the worst part of being a carer

Appendix E: Camera cover (Study two)



Appendix F: Interview Schedule (Study two)

The experiences of Young Carers: A photo elicitation study

Interview Schedule
Materials: Photographs x 2 OR displayed on tablet
Italics: Questions for young carer
Within [ ] : instructions for researcher
Bold: Instructions/introduction/debrief

Introduction
Hello,
Thank you for coming along to talk to me today. As you know I'm from the University of Bath and I'm doing some research with Young Carers like yourself. I just want to remind you about what is going to happen. I have the photos you have taken here and in moment we'll start talking about them. I'll ask you some questions about the photos and then may ask you some other questions too. I want to remind you that you can take your time with the questions and showing me your photos. We can pause or stop at any time, just ask me. I may take some notes during our talk, but I will still be listening to you. *Does that all sound ok*?

And are you ok for me to record our chat on this recorder?
[N – Explain that I will be taking notes]
[Y – Turn on the Dictaphone and begin interview]

General background
So first I'd like to ask you a few questions about you…
Could you tell me a little bit about yourself? (Age, siblings, school year, ethnicity)
And can you tell me about the person, or people, you care for? (Relation, health condition, how long for)

Photo elicitation (main interview)
I have the photos here that you took using our suggestions and questions, I'd really like you to tell me about them. Which would you like to talk about first? [Allow choice, if unable to decide, choose one]

Prompts for photos:
Why did you choose to take this photo?
When was this taken? (Time of day, weekend)
Where was it taken? (At home, at doctors, in bedroom, in bathroom, kitchen etc.)
What/who does it show?
What is the story behind this photo?
How does this photo make you feel when you see it?
Can you remember how you felt when you took it?
How do you cope with/deal with the image/situation here/that you have just told me about?

Additional questions to consider during photo elicitation – or after if not addressed during
What helps you most when you are feeling….because of your caring?
Does anyone else know about the help you provide?
Do your friends, teacher, other adults know – help?
Does being a carer help you in anyway?
Is being a carer unhelpful in anyway?
Extra photos (if taken by participant)

I have the extra photos you took here, and I'd really like you to tell me more about them, like we have with these other photos. ***Is that ok? Which photo would you like to start with/which is your favourite from these?***
[Allow young carer to select photo, if shy, choose one]

Can you tell me what this photo is of?
Why did you choose to take this photo?
Can you tell me if there is story behind it?
What does this show about caring?

Closing & debrief
Is there anything else you would like to say about the photos or any of the other questions I have asked? Anything you are surprised I didn't ask you about? Or anything about being a carer that is really important to you or you think I should know?

[Turn off Dictaphone]

Thank you very much for answering all those questions for me and telling me about your photos. I know it can be hard to talk about sometimes. We are all finished now. Here are your photos for you to take home with you and a bit of information that you might like to read through once you get home. [Provide photos and debrief information sheet]

Appendix G: Correlation matrix of all variables (Study three)

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Multiple Deprivation Index	-												
2. Social Support	.120	-											
3. Family Support	.082	.381***	-										
4. Problem coping frequency	.075	.301**	.326**	-									
5. Problem coping efficacy	-.045	.434***	.368***	.675***	-								
6. Emotion coping frequency	-.317**	-.080	-.080	.179	.097	-							
7. Emotion coping efficacy	-.185	.090	.072	.142	.256**	.591***	-						
8. Avoidant coping frequency	-.093	-.135	-.440***	-.026	-.109	.389***	.151	-					
9. Avoidant coping efficacy	-.013	.069	-.133	-.024	.148	.052	.294**	.229*	-				
10. Life events	-.231*	.003	-.226**	.211*	.060	.409***	.293**	.466***	-.057	-			
11. Resilience	.018	.580***	.748***	.407***	.429***	-.134	.029	-.375***	.028	-.131	-		
12. Perceived stress	-.128	-.231**	-.512***	-.095	-.213*	.512***	.169	.585***	-.062	.480***	-.538***	-	
13. Benefit finding	-.200	.394***	.354**	.417***	.339**	.119	.204	-.031	.114	.085	.566***	-.250**	-
14. Hair cortisol concentration	.106	-.097	-.142	.042	.041	-.050	-.020	.034	-.184	.039	-.174	.082	-.191

Note: *$p < .05$; **$p < .01$; ***$p < .001$

Appendix H: List of conditions cared for by young carers and frequencies per study (Studies two and three)

Health condition	Study two *n*	Study three *n*
Mental health & behavioural		
Unipolar depression		6
Bipolar depression		5
Anxiety		2
Autism	4	5
ADHD	1	4
Asperger Syndrome	1	
Undefined mental health condition	2	1
Digestive		
Coeliac disease	2	1
Irritable Bowel Syndrome		1
Crohns		1
Cardiovascular		
Hypertension		1
Angina		1
Postural Orthostatic Tachycardia Syndrome		1
Heart Attack		1
Heart Disease		2
Endocrine/Metabolic		
Type 2 diabetes		1
Hashmito's		1
Autoimmune disease		2
Ear, Nose and Throat		
Hearing Impairment	1	1
Sleep Apnoea	1	
Eye conditions		
Visual impairment		1
Gynaecological		
Endometriosis		1
Fibroids		1
Musculoskeletal		
Arthritis		5
Curvature of the spine		1
Back pain	1	3
Knee pain		1
Sciatica		1
Hypermobility		1
Carpal tunnel		1
Spondylitis		1
General mobility issues	2	1
Neurological		
Cerebral Palsy	1	
Alzheimer's / Dementia		1
Epilepsy	1	1
Motor Neurone Disease		1
Multiple Sclerosis	1	
Narcolepsy		2
Fibromyalgia	2	6
Learning disability	1	1
Dyslexia/ Dyspraxia		2
Respiratory		
Asthma		1
Cystic Fibrosis		1
Chromosomal		
Down's Syndrome		1
Rett Syndrome	1	
Ehlers-Danlos syndromes		2

Skin		
Eczema	1	
Other conditions		
Chronic Fatigue Syndrome	1	
Complex Regional Pain Syndrome	1	
Secondary breast cancer		1
Undefined physical disability		2
Undefined chronic pain	2	